Working Together, Learning Together

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Sofie Sergeant

Working Together, Learning Together

Towards Universal Design for Research

Gompel&Svacina

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Gompel&Svacina

In memory of Huug

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Working Together, Learning Together
Towards Universal Design for Research

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Geboren te Gent, België

promotoren: prof.dr. G. Van Hove

prof.dr. P.J.C.M. Embregts

copromotor: prof.dr. A.P. Schippers

Table of content

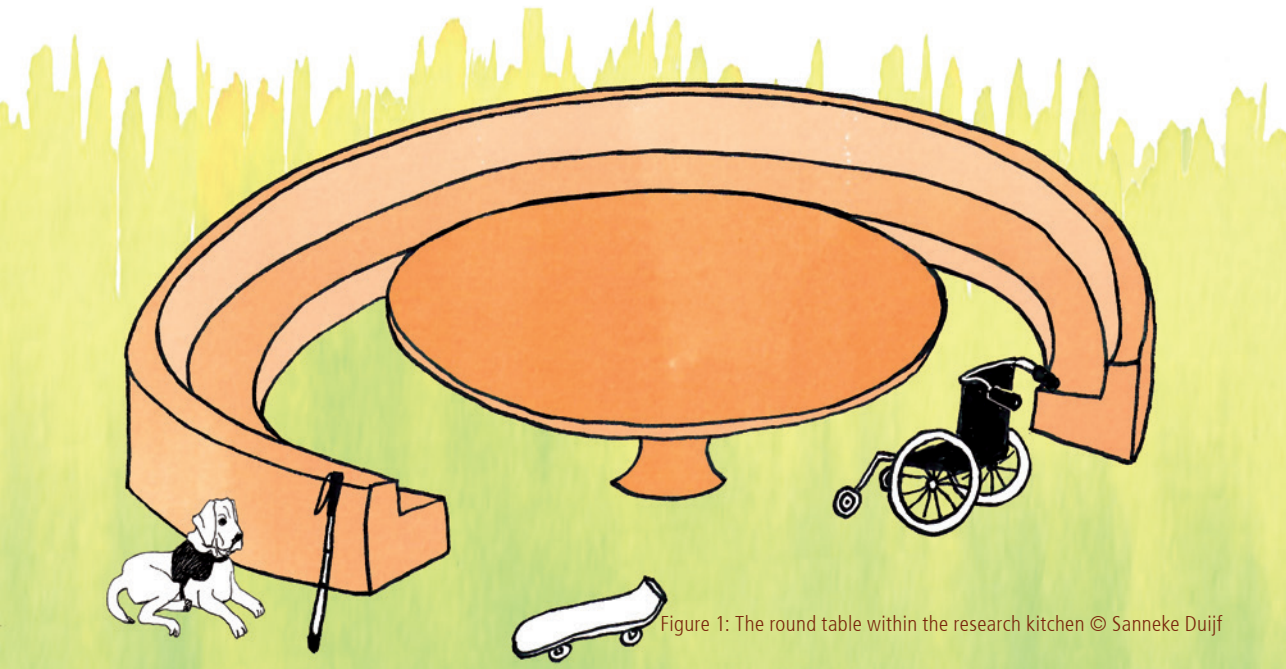
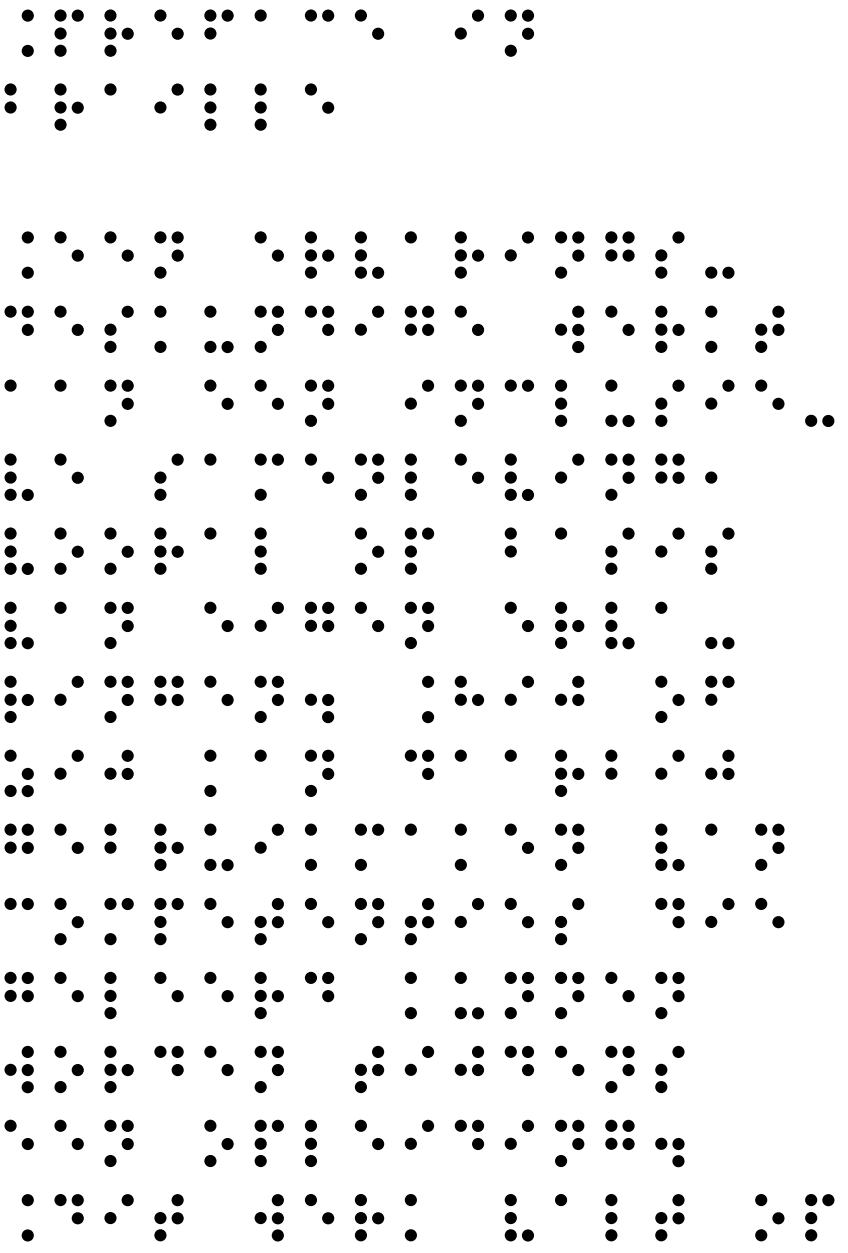
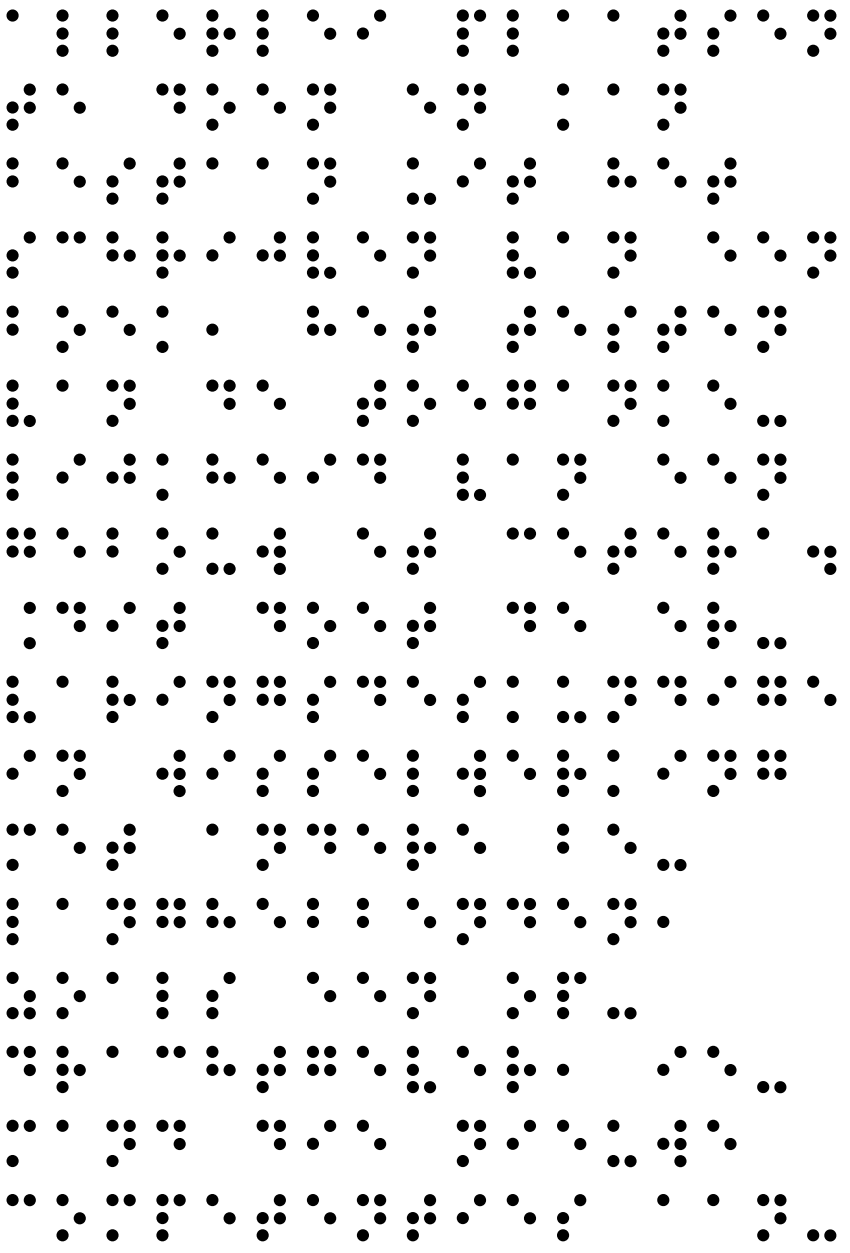


Figure 1: The round table within the research kitchen © Sanneke Duijf





Preface

Welcome to my PhD dissertation created through and around my research on inclusive research and developing training for inclusive research teams.
My research focuses on the exploration of inclusive research and analysing what questions, themes and issues inclusive research teams are facing. Through this research project I had the opportunity to enter different inclusive 'research kitchens' and to join the meetings and roundtables within those kitchens (see Figure 1). From these experiences we created a training together with researchers with academic background, researchers with experiential knowledge, designers, experts from different disciplines.
In my own way I hope to have done justice to the stories and the trust that all people I have encountered in this research work gave me. I am truly grateful for all the connections, blockages, challenges and openings.

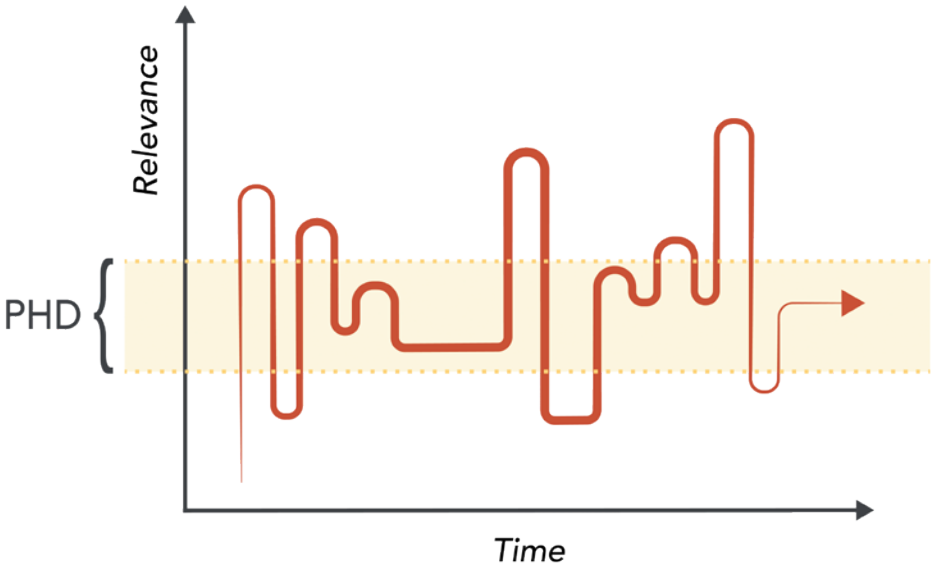


Figure 2: My PhD road over Time © René Krewinkel

In Figure 2 my PhD journey is expressed in a graphic made by one my 'compagnons de route' since years now, René Krewinkel. As you can see, some passages on the road were not relevant for inclusion in this manuscript. Other data, ideas that grow from this PhD seem very relevant, but I had to put the line somewhere: I decided to leave them out of this manuscript and to take them with me for exploration in future research.

I don't know where exactly my journey started but I think I have to go back to the time I worked for KONEKT, a Belgian network organisation that works for and with people with disabilities, towards an inclusive society. I developed and organised training sessions for people with disabilities and their allies. In that time, I created courses on social skills, dementia, mourning, palliative care, addiction and many other – abstract and delicate – themes, together with colleagues from many different fields. I discovered during these training sessions I needed very diverse training materials. So, I started working together with the artist Saar De Buysere. Prof. Dr. Geert Van Hove asked me to work on a PhD on these picture books. The problem was that I was enjoying the work of creating picture books so much that no scientific articles were written in that time.

Instead, we co-created the following materials:

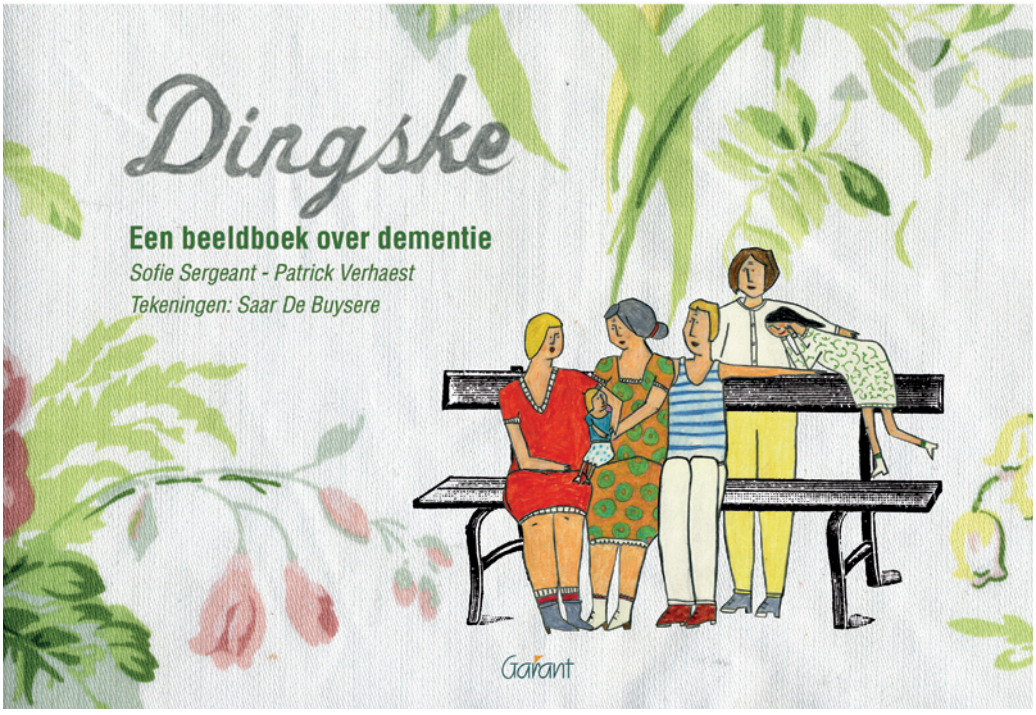


Figure 3: Dingske: a picture book on dementia (Sergeant, Verhaest & De Buysere, 2010) © Saar De Buysere

Figure 4: Nu en straks: a picture book on palliative care (Sergeant & De Buysere, 2013) © Saar De Buysere

Figure 5: Et maintenant: a picture book on palliative care, translated into French (Sergeant & De Buysere, 2014a) © Saar De Buysere

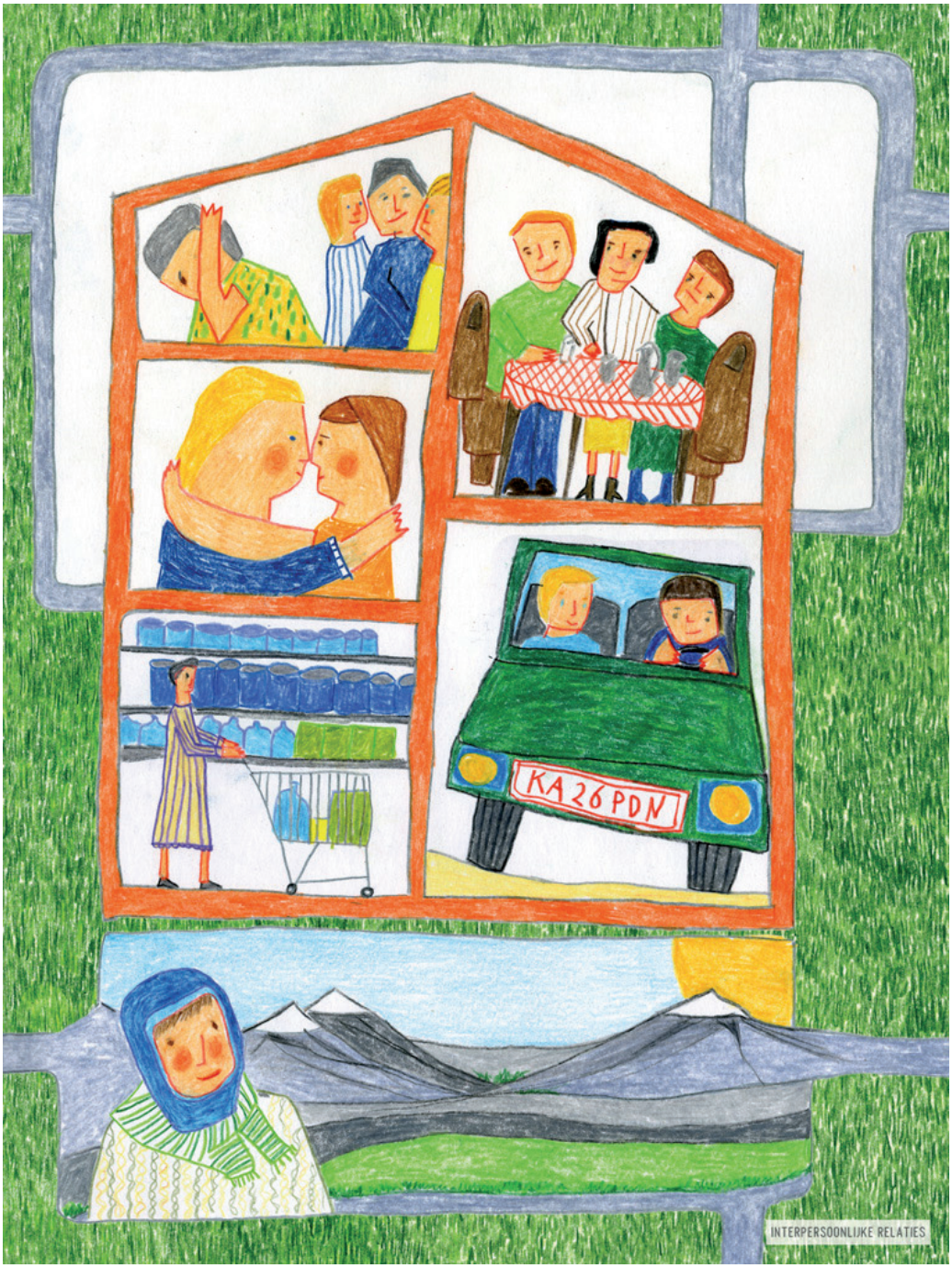


Figure 6: Achter de rouw: a package of 8 large puzzle pieces on mourning (Sergeant & De Buysere, 2014b) © Saar De Buysere

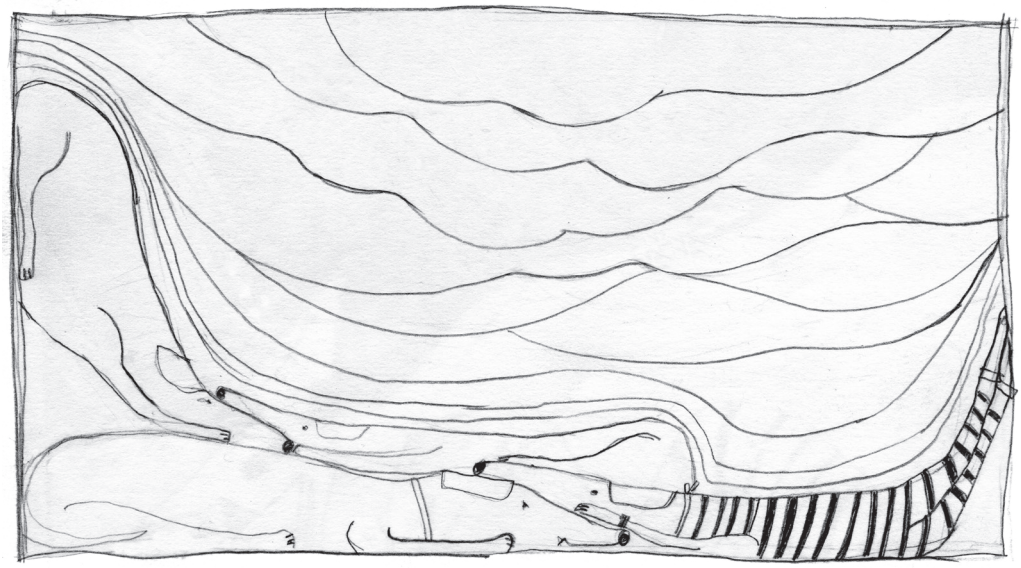


Figure 7: Young dogs: a graphic novel on fear (Sergeant & De Buysere, 2014c) © Saar De Buysere

In the process of creating picture books, I met Irene Tuffrey-Wijne in Ghent. She told me about her experiences in co-creating and co-researching with people with disabilities. This was an eye-opener for me, although I needed time to learn what this co-creation really implied…Until then, I shared our work: we organised testing sessions whether our drawings would 'work' or not. But to be honest, we organised this in the last phase of our research work: editing before printing.

Whilst living in Berlin, I was contacted by Prof. Dr. Geert Van Hove. If I could create education and training materials for Disability Studies in Nederland (DSiN). Subsequently, I was introduced Alice Schippers – the director of DSiN – and I started my engagement for the DSiN-foundation as education coordinator. In 2015, we moved from Berlin to Soestduinen, in The Netherlands. And in 2016 I was asked by Geert Van Hove and Alice Schippers to join the research project 'Working Together, Learning Together' (WTLT), a research project funded by ZonMW which aimed at researching the participation of people with disabilities within the National Programme 'Gewoon Bijzonder' research projects. The research work for WTLT comprised a deadline: finishing my PhD in 2020. Geert and Alice smiled: we had a deal and a deadline.

'Working together, learning together' is carried out by DSiN, Academische Werkplaats Leven met een verstandelijke beperking (AWVB) Tranzo and the LFB.

My research partners in this project were:

- Joint research partner Henriëtte Sandvoort (LFB)
- Dr. Kim van den Boogaard (postdoc researcher Tranzo)
- Prof.Dr. Alice Schippers, Disability Studies / VUmc Metamedica, co-supervisor of my PhD
- Prof. Dr. Petri Embregts, Tranzo, Tilburg University, co-supervisor of my PhD
- Prof. Geert Van Hove, VUmc Metamedica, supervisor of my PhD
- Joost Blommendaal (LFB)

Together with Henriëtte Sandvoort (trainer and researcher with experiential knowledge, LFB) we started our journey of four years (2016-2020) working closely together as 'researcher duo'. The result of what we learned is described in my PhD dissertation. Of course, there is much more to tell beyond the chapters in this dissertation, but it is a carefully constructed beginning.
Working closely together was for both Henriëttte and myself a very exciting experience. We had hilarious moments; as well as breakdowns. But through the years, through all our encounters and 'battles', working together as a duo only got better and better, as depicted in Figure 8.

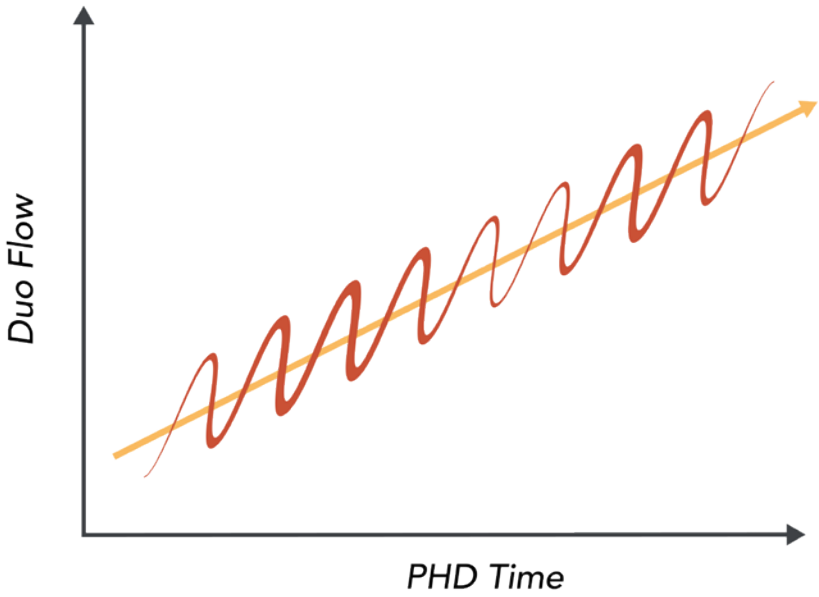


Figure 8: We had joy, we had fun, and we had our battles © René Krewinkel

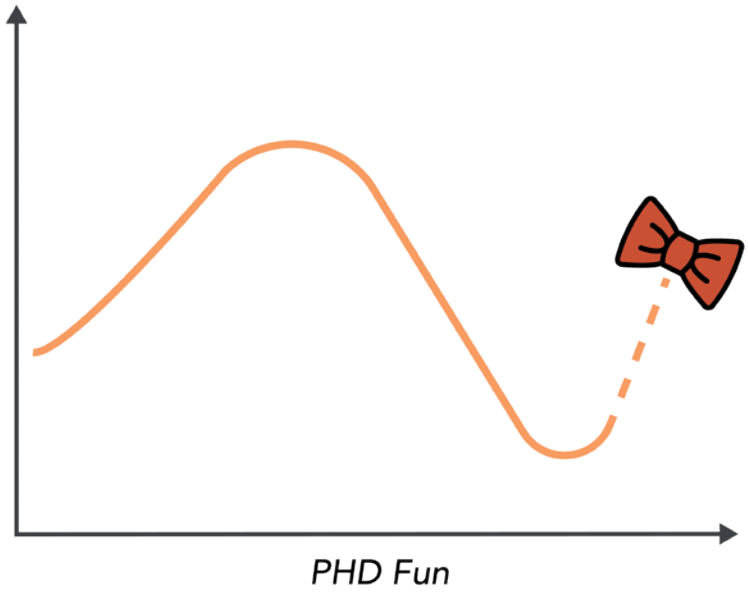


Figure 9: The funfactor during my PhD-time © René Krewinkel

As I am writing my PhD dissertation I look back at the whole process and also at the last period of feverish writing. In Figure 9 this overview is depicted.

It took me time to feel 'at home' in the WTLT-research project. Once I felt at home in my work with Henriëtte and other colleagues my work felt as an adventure with impact, a life-changing event.
ZonMw provided extra support for the implementation of our research work and the training we created. So, from January 2020, Henriëtte and I searched for more people to join our training-team.

I will introduce them shortly:

- Bernadette Wijnker-Holmes: researcher
- Andries Lever: trainer with experiential knowledge
- Sanneke Duijf: social designer
- Bob van den Berg: graphic designer with experiential knowledge
- Rosa Stalenberg: student researcher
- Marjolein Olde Heuvel: social scientist and mother with experiential knowledge
- René Krewinkel: app and website designer, cartoonist
- Remco Mostert: writer and trainer
- Irene van Helden: communication manager

- Angela Hanse: office manager
- Mitzi Waltz: researcher, English native speaker
- Ellis Merkelijn: trainer and coach with experiential knowledge
- Marja Steegenga: trainer and coach

We are very proud of our team; we celebrate the diversity and all the talents we assemble.

But then… I had to leave 'my playground' and write my articles and dissertation. COVID-19 times broke out which actually helped me to focus: to sit behind my desk and write my dissertation. Sometimes this process felt lonely, but at the same time it was an opportunity to carefully capture our research experiences in qualitative research articles. Creating the quantitative graphics with René Krewinkel for this preface helped me to smile and embrace the silent times of reflection and writing. Finishing the manuscript gives me a great boost and I am relieved to finally be able put a bow around this PhD time period.

In writing my dissertation I purposely chose for open access publications and for embedding non-academic publications that are accessible for a broad public. Within the scope of the forlaying research work, social impact factor seemed to me more important than journal impact factor. Therefore you will also find photos, graphics, cartoons, films, blogs and vlogs in this dissertation. I will come back to this point in the discussion section on striving for a more accessible academic world, for more co-creation and for universal design for research.

Acknowledgements

My process of coming to understand more about inclusive research has been a relational process. The many people I encountered and shared paths with during my personal and professional journey are uncountable and precious.

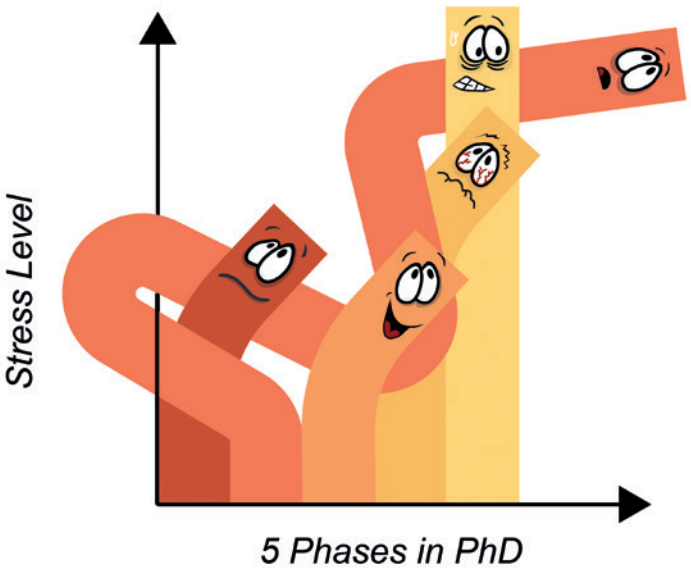


Figure 10: The 5 phases in my PhD © René Krewinkel

Living in Berlin a few years ago, I had a late-night encounter with my dear friend and colleague Lisa Pfahl in Berlin-Kreuzberg. From this encounter I learned that a PhD has its phases and that I was stuck in one of them. In Figure 10 the five interfering and entangled stages are depicted.

1. The first stage I call the stage of 'Getting in lane'. In this first stage the researcher needs to decide on the focus of the research work and therefore needs to anticipate and make choices. I think it is clear to the reader already that this first stage took ages in my case.
2. The second stage is also a tough one. Lisa Pfahl diagnosed my situation with the term 'Fokussierungskrise': the problem of 'staying focused on your research question and not to wander away from that'. I was happy to accept her diagnosis by that time: it had a name and she was concerned I was not the only one to suffer from this.

3. Phase three I call the 'Champion phase'. In many different occasions we had a feeling *"yes, we are doing something great together"*.
4. But those victory moments often were abruptly overwhelmed with feelings of: is this important enough? Is my research work doing any good, bringing any change? I name this third phase the 'Existential and motivational crisis in research phase'. My family and friends talked me through these crises.
5. Stage five – the 'Sit still phase' – sometimes was the most frustrating of all: the research work was done, and I had to sit down on a chair, and write it up.

I need to thank many people for their patience, for listening and for their relentless support in the journey towards my PhD dissertation.

This research project was funded by ZonMw within its national programme for people with disabilities, 'Gewoon Bijzonder ('Just Special'). The aim of this programme is to improve care and support for people with an intellectual disability, multiple disabilities or acquired brain injury, so that disabled people can function in society with greater independence and more control. I thank ZonMW for their trust and the necessary space they gave me to grow as a researcher.

I thank all the members of inclusive teams who have shared their stories, questions, laughter and tears. I thank all the participants of the training we created. For your trust. For your efforts to make this project happen. For your engagement. Thank you.

When I have finished this work, it is by standing on the shoulders of Giants: my supervisors, Geert Van Hove, Alice Schippers and Petri Embregts. Thank you for forming a team and creating a space of constructive feedback and warmth in which my confidence could grow. Thank you for your meticulous supervision, for the many online calls, for the meals we shared together and the good conversations along the path. Thank you, Geert for sharing your erudition and having been my inspirational guide for more than 20 years.

I thank my colleagues of Disability Studies in Nederland. Alice Schippers, for her clear vision and strong engagement in infiltrating with Disability Studies ideas in all sectors of society. Gert Rebergen, for his passionate and authentic support and for his constructive management. Minne Bakker, for being there when I needed a sparring partner to consider ideas and for helping me focus and structure. Irene van Helden, for her intense belief in the importance of this project and for her warm support in every stage of my PhD. Angela Hanse, for saving me with 'hands on' actions on crucial times.

I thank my DSiN-colleague-PhD-researchers Olga Múries, Leendert van de Merbel who wrote the 'Preface in braille' page in this book, Miriam Zaagsma, Hanna Peels, Moges Wubie, Eric Wilms and Irene Caubo for the various inspiring intervision sessions, meetings and support. Wish you all the best of luck in your future (research) work.

Jacqueline Kool and Ben van der Hilst, for your wisdom and wine, for your warmth and wondering.

I thank Iris Cuppen and Jurgen Wiegeraad for creating the beautiful introduction film: Henriëtte and based up our research work, our story and training on this film. Paul and Beatrijs Verhijen-Timmermans, thank you for trusting me with your Cabrio and for the CRF service (Convertible Rental only for Friends) .Hanna Peels and Beau, Elisabeth De Schauwer and Patrick Schelfhout, Kim van den Boogaard, Elsbeth Taminiau, Roy Brown, Esther Joosa, thank you for being my co-author and for coaching me to grow in writing my research articles.

Koen Deweer, Katrien De Baets, Maaike Hermssen, Meria Bakker and Wouter Blom, Jan Troost, Gustaaf Bos, Gerda van Wees, Mats Gorter, Anne Ligtenberg, Jan Boudewijn, Bert Janssen, Selçuk Gürişik, Carlijn Odijk for creating opportunities to work and write in peace and for joining me in those times.

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I thank the team of the Cabriotraining for co-designing our training. Sanneke Duijf, thank you for your beautiful artwork: your illustrations are an indispensable part of the training materials, the website and this dissertation text. Remco Mostert, thank you to support me in creating a 'failure-free environment' for our research group, to build up a solid structure and for writing up the manual and create oversight in the creative chaos of all the training materials we gradually assembled. René Krewinkel, thank you for endless inspiration and hard work in creating our website, app and for your great cartoon work. Bob van den Berg, thank you for your sometimes silent and sometimes not so silent support. And, Bob, it's ok: you can be the president of the Cabriotraining. Marjolein Olde Heuvel, thank you for your precious time and your powerful engagement in this team. I thank all the researcher duos we have formed sofar and in the near future, for your engagement and for making the Cabriotraining a living vehicle that works.

I thank the LFB-team for all the brainstorm work we did together. This project was created because of your spirit and ideas, because of your network and your matchmaking talents.

I thank the people in my life who have been closest by my side.

Eerst een dankje aan mijn mama. Je leerde me dat de keuken het begin is van alles: de dag krijgt hier een ritme. Het is de plek van creativiteit, sowieso van tijd, van ontmoeting, samenwerking, kracht opdoen en vragen stellen. Jouw taal en die van jouw mama – onze mémé – hangt aan elkaar van spreekwoorden en metaforen. In mijn proefschrift staat de metafoor van de onderzoeks-keuken centraal – en die ontleen ik aan jou en mijn kindertijd. Dank je voor je onvoorwaardelijke liefde. Voor je zijn. Voor je stoverij, je opgerolde koek, je clafoutis met kersen, je Mia Ballet soep en je onovertroffen frietjes. Je leerde me dat taal niet alleen uit woorden bestaat maar uit aanrakingen, beelden, geuren en smaken.

Dankjewel papa. Dankje voor je humor, droog en van het label 'Appellation d'Origine Contrôlée'. Merci ook om niet alle klimop uit onze tuin te snoeien terwijl ik aan het schrijven was.

Evelien, Hendrik en Hermien, mijn zussen en broer. Wat een heerlijk nest om in geboren te worden en op te groeien. De vertrouwdheid en het vertrouwen in dit nest heeft ervoor gezorgd dat ik me nu vrij en gerust kan bewegen ook in moeilijke, nieuwe en bij wijlen spannende situaties in mijn persoonlijk en professioneel leven.

Mijn kinderen Hannah, Anton en Jolien. Dank om de afgelopen jaren niet 'Kind in Nood' te contacteren en dapper jullie plan te trekken als ik (alweer) aan het werk was. Ik ben ontzettend trots op jullie 'joie de vivre', op jullie lef en ongebreidelde talenten.

Sven. Mijn man. Woorden zeggen niet genoeg. Maar dank om uren te luisteren en om mij af en toe te ontvoeren zodat mijn hoofd wat lichter werd.

Thanks to all my relatives and in-laws for your support.

Thanks to my dear friends from Ghent (with a warm hug for my 'Maria Goretti chiro maatjes) – Berlin (my lovely neighbours and the world famous 'Sherryclub') – Soest (the world famous 'Breiclub Het Steekje Los'), and to my friends from all the places in between. One special thanks goes to my friends connected in our so-called 'Korsakov' group: my group of 'old' students from UGent 'orthopedagogiek' who stay young in ideas and who are the best friends in the world.
I am very grateful for the cooperation with Griet Vereecke, Multimediateam Pluryn, KONEKT, De Lovie, Tabor and Joint Projects. Thanks to their support, we were able to create the final chapter of my dissertation. Thanks to Brailledrukkerij Blindenzorg Licht en Liefde vzw we could implement the braille page in this book. Thanks to the support

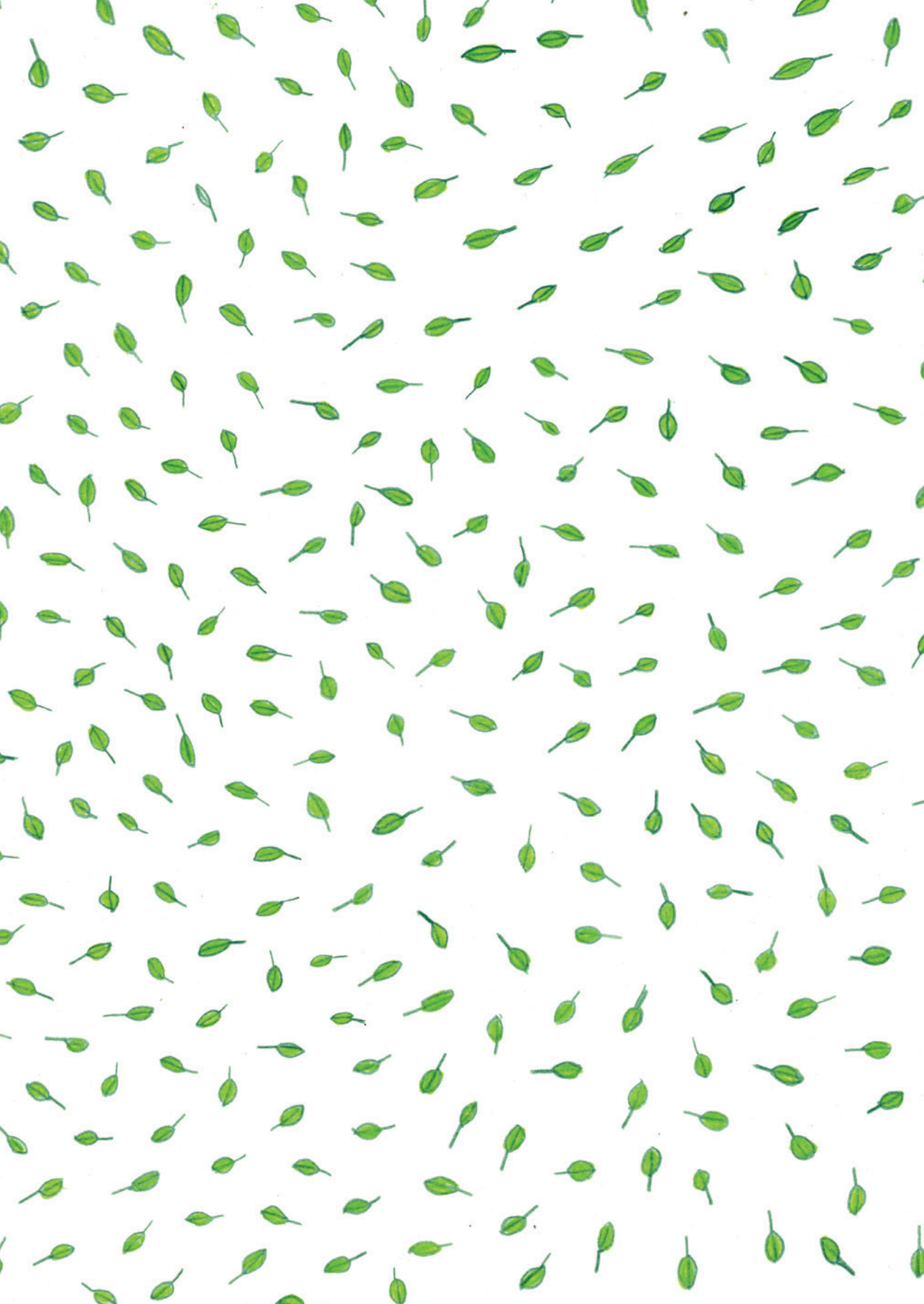
of Stichting Marguerite-Marie Delacroix and WerkSaam Westfriesland we could create this colourful book and we could try to 'walk the talk' during the PhD defence.

Saar De Buysere. Thank you for reading my thoughts for forgiving me my constantly changing ideas and plans and for creating this dissertation to a whole with colours and illustrations that go back to Dingske and other picture books we created together.

Huug van Gompel (+), Stephan Svacina, Eefke van Sas and the Gompel & Svacina team are for me the best and most reliable publishers in the world. I thank you for the cooperation. I thank Huug for all the years of collaborative work, for your spirit, for your life's work, for the twinkle in your eyes.

Henriëtte Sandvoort. For our strong partnership in this research work. For teaching me about the importance of experiential knowledge. For your friendship, trust and for your keen eye.

Sofie
September 2016 – December 2020



Chapter 1 – General introduction

1.1 Inclusive research

In the last few years many initiatives were created for improving the participation of people with a disability label in the Netherlands: for instance the Social Support Act (WMO), the Participation Act, and the ratification of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) in 2016. These laws state that *"inclusion and participation are general guiding principles and that besides being a right of persons, it is also an obligation of governments"* (Kool & Sergeant, 2020, p. 35).

Although these laws are an important and very welcome articulation of the rights of persons with disabilities and of the strengthening of their position, we also must acknowledge that the quality of life of people with a disability and their participation in the social domain can be greatly improved by comparison with the average Dutch citizen (Meulenkamp 2011; Hemstede 2013; Kool & Sergeant, 2020).

Internationally we learn that people with the label intellectual disabilities (ID) frequently live and work in separate areas (Kliewer, Biklen & Petersen, 2015; Bigby, 2008) and are often perceived as belonging to a different category, as people 'who lack something'. People with ID testify they still often feel they do not belong in society: they often feel excluded from cultural and social life, and from education and work (Atkinson, Jackson & Walmsley, 1997; Scior & Werner, 2016). Two categories tend to emerge: 'them' (people with disabilities) as compared to 'us' (people without disabilities) (Van Houten, 2004). This process also seems to go the other way, with people with ID seeing themselves as 'us' and outsiders to their world e.g. staff, researchers and others without ID, as 'them' (Bricher, 2000). In our research journey for instance we heard people with ID say: *"they don't understand people like us"* or *"people like us can't do this"* or in a positive way: *"I am proud to be a self-advocate; they need our advice"*.

People with ID have often also been excluded from involvement in the design and implementation of research that directly concerns them. In research contexts, little recognition is found for the value of life experience in knowledge creation (Budge et al., 2016). Although in recent years the concept of inclusive research has become more widespread, people with disabilities still tend to be mainly involved as participants, not as researcher colleagues with power and control (Buchner, Koenig & Schuppener, 2016). Academic workers often have little experience in co-creating with experts by experience (Johnson & Walsmley, 2003; Nind, 2014; Coemans & Hannes, 2017).

However, there is growing evidence of the importance of working together with experts by experience in research in so-called 'inclusive research' (Nind, 2014; Buchner, Koenig & Schuppener, 2016; Embregts, Taminiau, Heerkens, Schippers, & Van Hove, 2018). Through inclusive research, socially excluded groups – such as people with disabilities – can engage and learn in joint research work and this co-creation process can catalyse more empowerment and inclusion (McDonald & Stack, 2016; Buchner, Koenig, Schuppener, 2016; Stack & McDonald, 2018).

Inclusive research *"involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or the distribution and application of research findings" (Bourke, 2009, p.458).* Within inclusive research, people with disabilities work together with academics as *"instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users"* (Walmsley & Johnson, 2003, p.10).
Walmsley and Johnson put forward five major principles of inclusive research. I think these principles are crucial markers when we speak about inclusive research. People with disabilities:

1. have ownership over the research questions;
2. are collaborators in doing the work;
3. exercise some control over the process and outcomes;
4. can access questions, reports, and outcomes;
5. the outcomes of the research must further their interests, that is show relation to areas commonly associated with participatory or emancipatory paradigms. (Walmsley & Johnson, 2003, p. 9-10)

With the work of the 'Co-Researcher Collective'[1], the five principles can be illustrated:

1. Ownership over the research agenda is expressed in the following quote with *"I want people to know that we have hopes and dreams just like everyone else:" "I want a voice to be heard and for people to know that we have hopes and dreams just like everyone else. Our lives are just as much fulfilling and joyful and happy and fun as anyone else's lives. We have challenges, and things are difficult at times and our lives will be cut short and some definitely will be shorter. I live myself with a life-threatening illness and at any time your life can be cut short – just like that – but*

[1] The Co-Researcher Collective created the film about 'Living Life to the Fullest', a research project which seeks to forge new understanding of the lives, homes, desires and contributions of young people labelled with life-limiting or life-threatening impairments: https://www.youtube.com/watch?v=Ofb4MaLHz8k&feature=youtu.be

actually it makes me want to live my life to the full just as much more." (Spurr, R., C. In: Living Life to the Fullest: The Co-Researcher Collective, 2018)

2. Collaboration with others can be very empowering and catalyses feelings of belonging and contributing, as this co-researcher explains: *"It gives me a purpose and a belief that both I and others with life-limiting or life-threatening impairments have important, relevant things to say and add to our society. What is this discussion surrounding the understanding of disability in general? Research is also a way to connect with others in similar circumstances and gain a unique perspective into what their world is like. I found the research both illuminating and empowering as I hear the narratives that challenge the current understanding of young adulthood and disability and stories that echo and reinforce my own experience. Being a young disabled adult can be lonely and the converging of voices is a powerful step away from that loneliness."* (Whitney, S. In: Living Life to the Fullest: The Co-Researcher Collective, 2018)

3. Control over the process and outcomes is expressed in the following quote: *"Who is in a better position to draw out and articulate the desires, hardships and experiences of young people with life-limiting or life-threatening impairments than us, and the young adults we are collecting data from. Not only is the data we collect more authentic and first-hand, but it allows a further insight into living as a young disabled person by asking questions not only about the difficulties, but about their lives as a whole."* (Whitney, S. In: Living Life to the Fullest: The Co-Researcher Collective, 2018)

4. Accessibility can be tackled in various ways. One way is by introducing the arts: *"Together, we may seek to improve the lives of young disabled people with life limiting conditions. I hope to acquire valuable new skills and experiences whilst also building my self-confidence, which is something I really struggle with. The aim of the project is to use the arts to understand the lives of young disabled people living with life-limiting conditions by demonstrating that our experiences, skills, knowledge and talents are of value to the community."* (Aimes, C. In: Living Life to the Fullest: The Co-Researcher Collective, 2018)

5. The outcomes and the implementation of the research results must further their interests: *"I've answered loads of questionnaires, loads of surveys about my condition and my life. But I've never been asked how I feel about my life and how I feel about my future. And if my life limiting condition impacts how I think and feel in any way. So, I know this project is a great opportunity to really understand what's on the minds of young people with these conditions and what their hopes and ambitions are, and*

that hopefully we find a legacy that will show that we are just like everyone else is. We have our insecurities. We have our ambitions. And this project will serve as a record of amazing things that we achieve..." (Vogelmann, E. In: Living Life to the Fullest: The Co-Researcher Collective, 2018)

The quotes from researchers of the Co-Researcher Collective are positive and full of energy. I embed them because they vividly inspire us in the making of inclusive research together.

Because, as Nind (2014, p. 84) states, *"it is clear when we stand back and look at inclusive research that its full potential is yet to be realized,"* adding that "*reports (on inclusive research) often lack detail on how participation was optimized, and critical self-reflection and shared reflection are needed"* (ibid., p. 86).

Therefore, I concentrate in my PhD dissertation through and around my research about inclusive research not on the WHY (because there is growing evidence in the Netherlands and abroad) but on the HOW of doing inclusive research. Before defining my research question, I want to warn/comfort the reader in this PhD-dissertation, I do not pretend to give answers to this how-question. In the forlaying PhD I focus on the how of doing inclusive research by trying to contribute to the exploration of possible roads towards how to conduct inclusive research and to the identification of important issues, conditions and wicked problems in engaging in inclusive research.

1.2 Research objectives and questions

Recent research (Bigby, Frawley & Ramcharan, 2014; García Iriarte, O'Brien, & Chadwick, 2014; Strnadová, Walmsley, Johnson, & Cumming, 2016) has identified a number of challenges and tensions related to engaging in inclusive research. The forlaying research work departs from the above point that inclusive research enriches the research process, research results and the lives of all people involved. We are aware of these important qualities, but we are at the same time very aware of the conditions and the hard work that comes with inclusive research. We agree with Walmsley and Johnson (2003, p.12) that honest discussion and debate on the real difficulties of inclusive research is an important issue.

Nind and Vinha (2014, p. 40) identify the following barriers to doing inclusive research

1. Attitudinal barriers
   This concerns *"funders' lack of knowledge or understanding, their inflexibility, their low expectations of what people with learning disabilities can do, and their failure to learn or change. There were also general attitudes about protecting people with learning disabilities or not valuing their input."*

2. Barriers in the social process
   This relates for instance to *"the barriers put up by universities protecting their territory, inaccessible calls to tender for projects and few routes into research for people with learning disabilities. Some barriers were put up by individuals and some were rule-based such as rules about tenders, formal ethics and governance requirements, online submission to journals, and the need for police checks."*

3. Material barriers
   Related issues here are *"transport and information, lack of funding for preparatory work (which was important to the cherished value of involving people with learning disabilities at all stages), inadequate funding more widely, and rules associated with people's benefits payments making short-term paid research risky."*

4. Within-person barriers
   This refers for instance to communication and literacy difficulties. Academic researchers admit gaps in their skills. A lack of curiosity is identified as a barrier for anyone. *"The problems associated with inclusive research do not lie with people with learning disabilities"* (Nind & Vidha, 2014, p.41).

Acknowledging both the importance of conducting inclusive research and the observed barriers on different levels, it is clear that preparations, well-reflected actions need to be taken. Positive research findings about the value of coaching and training teams in which researchers and experts by experience work closely together (Johnson & Johnson, 2009; Bigby & Wiesel, 2011; Bigby, Frawley & Ramcharan, 2014; Van Hove et al., 2016; Beresford, 2019; Embregts et al., 2018; Strnadovà et al., 2014; Chapman, 2014) inspired us to carry out our research project, 'Working Together, Learning Together' (WTLT). This project aspires to bring to light catalysing ingredients for organising inclusive research. Based upon the above research findings about the value of coaching and training and based upon our own experiences in inclusive research (Embregts et al., 2018) we decided to develop and provide training to inclusive research projects, whilst reflecting on inclusive collaboration within our own project group. We created a new training because – to the best of our knowledge – training for inclusive research teams was non-existing at that time in the Netherlands.

From Nind and Vinha (2014, p.41) we learn that *"problems associated with inclusive research do not lie with people with learning disabilities"*. That is why we did not develop training and coaching for the researchers with experiential knowledge separately. Therefore, we (an inclusive team) created training and coaching for inclusive teams.

The forlaying research work aims to contribute to HOW inclusive research can be done. The following research questions have been developed from this research objective:

1. What are the catalysing ingredients and conditions for organising inclusive research in order to overcome attitudinal barriers, barriers in the social process, material barriers and within-person barriers?
2. Based upon these ingredients and conditions: what kind of training and coaching is needed?

In Chapter 6, I will come back to this research objective and the two research questions. Within this conclusive chapter I embed section 6.4 'Implications for practice & research' on HOW barriers can be tackled and what paths to be explored and researched in the future.

1.3 Ethics

"I never felt this way. I have never felt so at the right workplace. I now have the space to learn. I do not get the feeling that I am 'just' a co-researcher. We work together, based on our own expertise."
(Sandvoort in: Sergeant, 2019, February)

The Medical Ethics Review Committee of VU University Medical Centre (FWA00017598) confirmed that the Medical Research Involving Human Subjects Act (WMO) did not apply to this study and approved this study.

We followed the Disability Studies in the Netherlands Code of Practice in Research (Disability Studies in the Netherlands, 2017). This implies that we (researchers and experts by experience) co-created this study from the beginning: from setting up the research agenda, designing and conducting the research, creating easy-read versions of informed consent documents together, and writing and presenting collaboratively. This implies also that we acknowledge vulnerability in every person involved in the research work. Traditional ethics rightly stress the vulnerability of people with disabilities and the importance of avoiding of deliberate harm but in our code of practice it is embedded that this cannot be a reason to silence them, to exclude them from research.

Our work is embedded within this defined and formalised ethical framework, but ethical transparency and integrity can only be achieved in inclusive research "*when the researcher embraces reflexivity in every aspect of their work*" (Cocks, 2006, p. 264). I agree with Cocks that *"ethical frameworks, tools and methods cannot merely be a posture assumed in order to satisfy the requirements of academic and professional research; rather it is a*

position that should be declared by the researcher." (Cocks, 2006, p. 261) Seeking assent in the collaborative work requires the researcher to remain *"constantly vigilant"*, it requires time and constant effort: *"it is not something gained at the beginning of the research then put aside"* (Cocks, 2006, p. 257).
Henriëtte Sandvoort and I worked together intensely and from the start of this research project. The research process being highly relational and co-creational chafes at the fact that writing and presenting a dissertation is an individual matter. In Cocks words: *"It could be seen as exploitative as it was also the source of material for a PhD thesis, so was also carried out with an element of personal gain"* (Cocks, 2006, p. 260). I tried in my work to achieve balance that acknowledges the value of our collaborative work, the value of her voice and my own work as a researcher and personal ambitions. Henriëttes voice is also present in this dissertation through the columns, the blogs and the vlogs we made. This section also starts with a quote from a column. The quote above goes back to the concept of 'belonging', the space for the 'co-researcher' and the language we use in this matter. But I will cross that bridge when we come to it, later in my dissertation, in Chapter 4.

The work I can present today is thanks to the co-creation process with Henriëtte and with many others the reader will encounter throughout the dissertation text.

1.4 Methodology

"Do you know what I often get in return?
That I make it clear to people that research work is nothing more than looking for the answer to a question, using a certain method that you follow closely.
But – and that is an important one: it must be your question!
If you own the question, you also want to figure out the answer.
A completely new world has opened up to me: the world of researchers.
But as far as I am concerned, that world is close to normal life, where we want change."
(Sandvoort in: Sergeant, 2019, June)

We conducted a nationwide inclusive research project in the Netherlands called 'Working Together, Learning Together' (WTLT). WTLT employs action-oriented qualitative research methods. In action-oriented research *"emphasis is placed on producing knowledge that can be used by community partners to contribute to positive social change and the well-being of individuals, families and communities"* (Small & Uttal, 2005, p. 938.) Our research work involved a reflective practice of developing training for other inclusive research teams. We used action-oriented research because we aim to catalyse positive change by creating time and space for training (Kidd et al., 2017), and by

supporting trainers and participants to become more reflective in their work and collaboration.

Within the study, we developed and provided coaching and training to researchers with academic background and researchers with disability experience engaged in inclusive research projects in the Netherlands. In this process of coaching and training, we reflect on our collaboration and communication.

The study spanned four years and was comprised of four phases (see also Chapter 2). The phases are here presented as separate and chronological. In reality the phases were much more entangled. The iterative movement of the repetition of four phases is presented in Figures 11a and 11b.

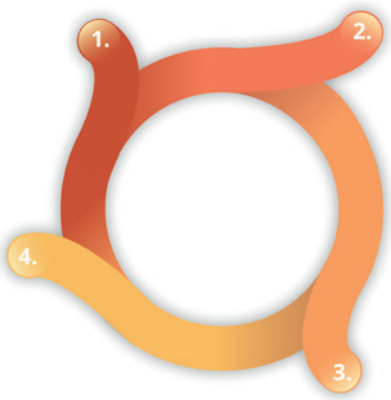


Figure 11a: Working Together Learning Together in 4 iterative phases © René Krewinkel

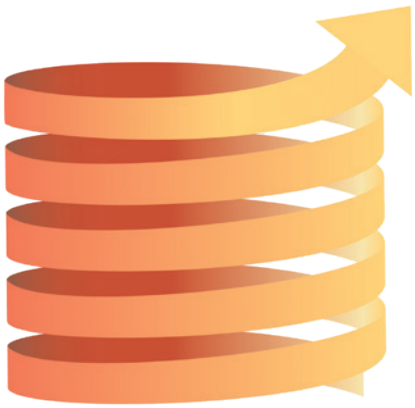


Figure 11b: WTLT improving our product with each cycle of four steps © René Krewinkel

Phase 1: Conducting open interviews in introductory meetings with ten research teams

Table 1 in Chapter 5 provides an overview of these ten projects. The ten projects were not chosen by us, but were part of a nationwide research programme. All projects were financially supported by the national funding organisation ZonMW, on the condition that they worked closely together with experts by experience. The training was based on literature review and on questions generated by the project teams, which could also decide how many training sessions they wanted. The researcher duo contacted the ten research teams to arrange introductory meetings. In this first meeting, the researcher duo introduced themselves and interviewed the project team members on their research questions and methods, on how people with disabilities were involved in the research, and on what questions, problems and needs for training they came across.

Phase 2: Creating and giving first training sessions

After each introductory meeting, the researcher duo started an inductive approach of building up, creating and giving the training. The first training and coaching sessions were built upon these questions.

Phase 3: Reflection and further development of training

Meeting colleague researchers, reflecting and exchanging, working in a larger and more diverse team, the training was further developed, and training was offered to more (diverse) research groups.

Phase 4: Implementation phase

The training becomes an ongoing permanent practice in order to make it sustainable and accessible for more research groups. Lessons learned are formulated; consequences for research and future practice are brought in discussion.

1.5 Chapter outline

Figure 12 – drawn by Sanneke Duijf, social designer and member of the team who developed the Cabriotraining (see preface: introduction of the team) – depicts the metaphor of 'cruising the sushi in a Cabrio'. The idea for this metaphor was born in an encounter with my PhD – supervisors in a Japanese restaurant, searching for a clear structure in my dissertation.

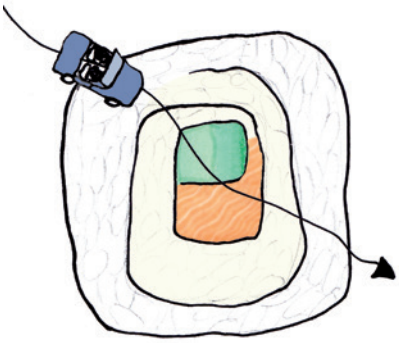


Figure 12: Cruising through the sushi © Sanneke Duijf

Our sushi roll has four layers and takes us from very small to the larger research field and social structures. Within every chapter, I will situate where we find ourselves in the sushi:

1. The heart of the sushi: the long-term and intense collaboration between the so-called researcher duo: Henriëtte Sandvoort and myself.
2. The second layer depicts the encounter of the researcher duo with two other researcher duos: Elisabeth De Schauwer and Patrick Schelfhout, Hanna Peels and Beau.
3. The third layer borders all the meetings we had with the different teams we met and trained.
4. The fourth layer brings us to the research field and the social structures in which we operate as researchers.

In my dissertation I invite the reader to join me on my cruise through this sushi. This ride, we undertake in a Cabrio. The idea for the metaphor of the Cabrio originates from the time Henriëtte and I learned to know each other. We found out we both love to travel, to be on the road – if possible – in open air, in close contact with the landscape and the world surrounding us. Upon this metaphor we created with Iris Cuppen our introductory film (see 2.2. On the road).

In chapter One I introduce our research questions and the conducted study within literature on inclusive research and the position of people with disabilities in our society.

In Chapter Two 'My close collaboration with Henriëtte Sandvoort', I start with zooming in on the heart of the sushi: collaboration between researcher with experiential knowledge Henriëtte Sandvoort and myself working together closely during all the phases of the forlaying study. I refer to our collaboration and team as 'the researcher duo' in my dissertation.
Chapter Three 'Creative Research Methods' cruises through all layers of the sushi: offering an insight in the richness of creative research methods enlarging the suitcase of methods of a researcher and setting the field for inclusive research work and universal design for research and communication.

Chapter Four 'Collaboration' explores the longterm relation within three researcher duos: layer two of the sushi. We aim to contribute to the understanding of how collaboration in inclusive research teams works and realises transformation in the way of working together and in the researchers, who are involved.

Chapter Five 'The Cabriotraining' disentangles the creation process of the Cabriotraining: the third layer of the sushi. In this chapter we elaborate on our joint learning route how to develop and provide training and coaching to inclusive teams on organising collaboration in the different stages of their research projects.

Chapter Six 'In conclusion' focuses on the fourth layer: what can we learn from our encounters in the research field and the social structures in which we operate as researchers. I summarise our findings through metaphors. We situate our conclusions within the broader research field, share limitations of our work and implications for practice and make suggestions for future research.

Finally, I terminate this dissertation with Chapter Seven. This chapter encloses a film we made together: a summary of this dissertation captured in a film. We chose not to create an easy-read-summary because that also excludes people from understanding the essence of my thesis. We chose for a film that gives a wide range of people the opportunity to understand what this dissertation is about, without too much effort. In the film we combine written and spoken words (Dutch and English), with music, sound and images. This choice for making a film is based on the principles of Universal Design for Research (Williams & Moore, 2011) in a sincere attempt to make our research work more accessible to a diverse audience, not only in the research process but also in the dissemination and implementation of the research results. This is also the reason why I wish to defend my dissertation in Dutch: to make my PhD defence accessible for all the people who joined me in my research work.

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Chapter 2 – My close collaboration with Henriëtte Sandvoort

"Building collegial work relationships are not optional extra but fundamental to collaboration"
(Bigby et al., 2014, p.63)

This chapter is based on:

Sergeant, S., Schippers, A., Embregts, P., van den Boogaard, K., Taminiau, E., Sandvoort, H. & Van Hove, G. (2020). On the road together: a researcher with academic background and a researcher with experiential knowledge working closely together. Manuscript submitted for publication.

2.1 Introduction

In the first Chapter we already introduced our inclusive research project Working Together Learning Together (WTLT). In the second Chapter we take a closer look at the collaboration within the heart of the sushi (Figure 13): the researcher duo consisting of Henriëtte Sandvoort and myself.

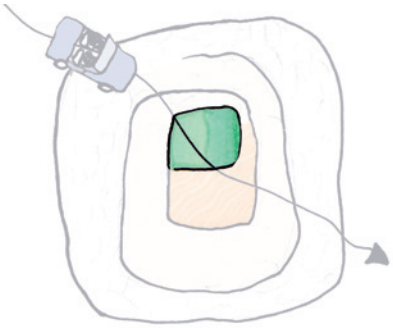

Figure 13: The heart of the sushi © Sanneke Duijf

We start with the introductory film, made by Iris Cuppen and Jurgen Wiegeraad. The film introduces the researcher duo and their collaborative research work by using the metaphor of the Cabrio and the Deep Blue Water. In 2.1. we embed this film and explain the metaphor. In 2.2. we enclose the article 'On the road' which focuses on the collaboration within the researcher duo and the themes, problems and issues they encounter.

Collegial work relationships are fundamental in inclusive research (Bigby et al., 2014). Bigby invites us to put more firmly focus on the dignity of risk than on protection. But at the same time, we acknowledge that building collegial relationships in inclusive research settings – respecting the multivocality – is very hard work (see also ethics, 1.3).

Considering the time, energy, efforts, training, money, conditions it takes for all research group members, engaging in inclusive research demands for a clear rationale and added value: *"While the importance of inclusive research is unquestionable, it is not a 'dogma' for research in the area of disability studies."* (Strnadova et al., 2014, p. 1).

Starting of my collaboration with Henriëtte, we took time to learn to get to know each other and to talk about our needs, conditions and goals. This process merged into the making of the film 'Two Researchers'[2] which can be easily found through the you-tube link or through scanning this QR-code (Figure 14):

Figure 14: Film *Two Researchers*

[2] https://www.youtube.com/watch?v=pOT2iRiEps4

I wrote the script below for the film 'Two researchers', inspired by the poem 'Lamento' written by Remco Campert. The idea for using the charts is based on the clip of Bob Dylan's 'Subterranean Homesick Blues'.

Two researchers
At the deep blue see
Looking at me
Looking at you

We seek the right words
We seek our way
At the deep blue see

Here, today
I never expected to be
Working together
Creating together
Riding together

Two researchers
At the deep blue see
Reading me
Reading you

We ask questions
We seek our way
At the deep blue see

Here today,
I never expected to be
Talking together
Searching together
Writing together

Two researchers
At the deep blue see
I florish
You florish

We look for structure
We seek our limits
At the deep blue see

Here, today
I never expected to be
Persuading together
Changing together
Dreaming together

Two researchers
At the deep blue see
You and I
Each with knowledge to share

Just as we should be
Together

In the film, the two researchers are introduced together with their joint research aim, their shared ambition, and the unknown of their research journey: how are we going to work together and accomplish the research task jointly.
The deep blue see stands for the unknown path of the research work. The Cabrio is a metaphor for the traveling and for the encounters with many different research projects throughout the Netherlands. On our journey we must learn to know each other, we must seek for HOW to collaborate and for HOW to attend our joint goals. Therefore, we need to be aware of our knowledge and talents, carefully matching this with the research tasks that are challenging us. Our joint ambition to make research work more accessible and inclusive is captured in the words: persuading, changing, dreaming.
We created the film to introduce our research work at the 2017 ECQI Congress in Leuven. After this congress we shared this film in many occasions and embedded the film in the training, which we started calling: the Cabriotraining.
In 2.2., the article on the intense and long-lasting collaboration within the researcher duo is embedded.

2.2 On the road together: A researcher with disability experience working closely together with a researcher with academic background

Abstract

The aim of this study was to gain insight into dilemmas and catalysing processes within the long-term collaboration between a researcher duo: a researcher with disability experience and a researcher with academic background. Their collaborative research work involves a reflective practice of developing training for inclusive research teams. The researchers both kept personal diaries on the focus of this article: the collaboration process. Inductive thematic analysis, individually and as a group of authors, was employed. Our results indicate that reasons to conduct inclusive research are clear and defendable, but necessary conditions include (1) experiencing belonging within the research group, (2) room for growing self-awareness and competence-building, (3) reflection and searching for various ways of communication, (4) sharing power and ownership of research process, (5) enough time to foster the above conditions, and (6) space for vulnerability in dialogue and collaborative work. These conditions catalyse the diversity-sensitive work in inclusive research, and the awareness of both stigma-related issues and the risks of tokenism.

Introduction

Working together with the people the research concerns is framed as 'inclusive research' (Sergeant et al., 2020). The term inclusive research is found prominently in the field of learning disability research (Nind, 2014). The authors use the definition of inclusive research by Walmsley and Johnson (2003, p. 9), *"research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers, and disseminators of research,"* as a basis for their research projects.

Inclusive research brings quality to the process and outcome of research, but research conditions should be taken into account to prevent tokenism and protect the wellbeing of all people included in the research team, as well as to ensure research quality (Strnadová et al., 2014; Chapman, 2014; Bigby et al., 2014). The current study is based on the principles from Walmsley and Johnson, who state that inclusive research (1) must address issues which really matter to people with learning disabilities, (2) must engage in research which ultimately leads to improved (family) quality of life for them, (3) must access and represent their perspectives and ambitions and (4) must take place in a research community that treats people with learning disabilities with respect (Walmsley & Johnson, 2003). This fourth principle implies that inclusive research must be built on respectful collaboration between people who have scientific knowledge and people who have more practical, experience-based knowledge. Therefore, *"time is needed to relax into relationships that are allowed to build slowly and organically"* (Chalahanová et al., 2020, p. 155).

Prompted by the United Nations Convention on the Rights of Persons with Disabilities, inclusive research is increasingly gaining attention (Embregts et al., 2018). But good intentions are different from actually conducting inclusive research in practice. With this article we engage with Nind's call for critical self-reflection and shared reflection within the field of inclusive research (Nind, 2014). We aim to provide a clear account of what it is we do when we collaborate, and why and how we engage in the collaborative production of knowledge between an academic and a person who was traditionally thought of as a participant or object of study (Duggan, 2020). Acknowledging that developing an equal relationship throughout the research process is a crucial departure point in this collaboration (Nind, 2014; Embregts et al., 2018; Duggan, 2020), this article aims at in-depth research into the search process for an equal relationship.

The general research question we explore with this study is: What themes, problems, and processes are observed in the process of a researcher duo (one researcher with academic background and one with disability experience) working together in a long-term and intense collaboration on an inclusive research project (WTLT) within which they have

developed, organised, and delivered training to inclusive research projects in the Netherlands.
Within this larger inclusive research project WTLT we have developed a training and coaching package for inclusive research teams. The development of this training is explored in the 'co-designing the cabrio' article (Sergeant et al., 2020). We learned from international research (Nind, 2014; Nind & Vinha, 2014; Strnadová et al., 2014) on the importance of training, teambuilding, talking things over and, collaborative reflection. The ultimate reason for developing this training is that training and coaching for inclusive teams was reported missing in the Netherlands (Sergeant et al., 2020).

The forlaying article is written upon the data collected in the time the researcher duo created the training together in an iterative process (Sergeant et al., 2020). In this process, the researcher duo shared all tasks and explored – on the road – what this collaboration needed and what themes and problems they encountered in their joint work to develop and organise the trainings jointly.

Providing insight into the critical reflection process of a researcher duo enables a deeper understanding of themes, dilemmas, problems, and catalysing processes involved in working closely together throughout the course of this four-year inclusive research study WTLT. We have concretised our general research question in sub questions:

- How have the researchers experienced their intense collaboration?
- What were the advantages and added value, which struggles and oppositions did they encounter within their own collaboration and in the wider context? How did they deal with these, and what is the value of their solutions for future inclusive research?

Providing insight into long-term collaboration within an inclusive researcher duo, we aim to inspire and support future inclusive research projects.

Method

Context

From 2016 to 2020, the seven authors conducted a nationwide inclusive research project in the Netherlands called 'Working Together, Learning Together' (WTLT). For this project we were asked by the Netherlands Organisation for Health Research and Development (ZonMW) to bring together questions and needs from 10 Dutch research (Sergeant et al., 2020). Based on the gathered questions and needs, we started creating the training in an iterative and inclusive research process. Therefore, WTLT employs action-oriented qualitative research methods. In action-oriented research "emphasis is placed on producing knowledge that can be used by community partners to contribute to positive

social change and the well-being of individuals, families, and communities" (Small & Uttal, 2005, p. 938.) Our research work involves a reflective practice of developing training for other inclusive research teams. So, the training was iteratively developed and organised upon the findings of this study. Therefore, we used action-oriented research, because we aim to catalyse positive change by creating time and space for training (Kidd et al., 2017), and by supporting trainers and participants to become more reflective in their work and collaboration.

So, the study spanned four years. Within this period, the researcher duo worked closely together and collected data in various forms. This article focuses on the collaboration between two researchers who worked together longterm and closely during this research project: the first author as researcher with academic background (Researcher 1) and the second author as researcher with disability experience (Researcher 2). The disability experience of the Researcher 2 refers to the fact that she lives with the label of intellectual disability and visual impairment. We refer to this pair of researchers as 'the researcher duo' in this article.

In Figure 15a the researcher duo is presented. The photo is a still from the film the duo made to introduce their collaboration and research project on developing training for inclusive research teams. The film can be downloaded from YouTube: https://www.youtube.com/watch?v=gaebCZ6D7FM.

Figure 14: Film *Two Researchers*

Figure 15a: Still 1 from Film *Two Researchers* © Iris Cuppen

Study design

The researcher duo worked together in both developing and giving a package of training and coaching sessions. During this process, the researcher duo collected data through participant observation. In participant observation, researchers are involved in the setting under study as both observer and participant (Reason & Bradbury, 2001; Maso & Smaling, 1998). Participant observation helps to identify and guide relationships, to learn about interaction, to examine how things are organised and prioritised in a setting, and to learn what is important to people (Kawulich, 2005).

The researcher duo also wrote reflections in the form of extensive fieldnotes in individual research diaries at least two times per week. The above mentioned sub questions served as starting points for our writings in the research diaries, kept during the larger study. As Bolger et al., (2003, p. 579) state, *"In diary studies, people provide frequent reports on the events and experiences of their daily lives. These reports capture the particulars of experience in a way that is not possible using traditional designs."* For this diary study, the researcher duo embedded an event-based design. A diary report was entered directly after every interview, training or meeting connected with the research project. This event-based design was most appropriate, because the process researched included triggering events often referred as critical incidents meaning events that the researcher duo experienced as very positive or very negative, aiming to unfold dynamic phenomena (Bolger et al., 2003., 590-591).

The researcher duo also decided to share several stories from these diaries in 35 published blogs and vlogs, which also form part of our research data. One blog was written by a journalist after he interviewed the researcher duo (Lingbeek, 2017). This process of creating blogs and vlogs provided an early opportunity to critically reflect on experiences not long after they had occurred. This was done to support our action research goals, to make our research work and results more visible and accessible to a broader public, and to be more transparent about methods and process of our study (Reason & Bradbury, 2001; Hookway, 2008; Mortensen & Walker, 2002). The blogs and vlogs included text, image, and video to reach populations otherwise geographically or socially removed from the researchers (Hookway, 2008). All blogs and vlogs were published (https://www.kennispleingehandicaptensector.nl) (in Dutch) on the site of Kennisplein Gehandicaptensector (https://www.kennispleingehandicaptensector.nl), the Dutch online knowledge exchange platform on disability, inclusion, quality of life, care, and support.

Analysis

Qualitative data therefore consisted of diary entries (field notes from participant observants), and the online blogs and vlogs, which included film and photos as well as text. A thematic analysis was conducted. Thematic analysis is the process of identifying patterns or themes within qualitative data (Braun & Clark, 2006). Four steps were taken during this process.

First, all research data materials were printed, listed, and numbered. Every researcher in the team of seven authors received a package of data. Materials were divided and shared in a way that ensured that every piece of the raw data was analysed by a minimum of two people, in order to integrate different perspectives and interpretations.

Second, researchers familiarised themselves with the data by repeated reading or viewing, searching actively for meanings and patterns (Braun & Clarke, 2006). Once researchers had familiarised themselves with the data, they engaged in coding the data, identifying important sections of text and attaching labels to index them (Braun & Clarke, 2006). In this second step, the data were open-coded, with data fragmented and titles assigned using short terms and phrases. Through this inductive thematic content analysis phase, individual researchers were asked to document theoretical ideas and reflections developed through immersion in the data, including values, interests, and growing insights (Lincoln & Guba, 1985). The aim of this step was to stay as close to the content as possible and to guarantee authenticity. The researcher with disability experience, who had already received extensive training in coding, used her computer screen magnifier and large print copies during the analysis phase.

Third, the research group gathered in the same room with their code lists and notes. The aim of the meeting was to code axially, whereby the open codes that belong together were sorted under a theme (Braun & Clarke, 2006). The group used Post-Its on a wall to shape an overview of themes identified and support the search process. In the joint meeting, the findings of the researcher with disability experience were shared first and guided the group as a whole, providing structure throughout the meeting. It is important to note that this research group has worked together on a long-term basis. Therefore, the atmosphere was collegial, while still being intense and critical.
This process of joint analysis was filmed.

In the last step, coding was selective, determining the relevance and coherence between themes (Braun & Clarke, 2006). The first author used the film of the joint analysis meeting, the photos of the Post-It-wall, all the different code lists, and notes of the researchers. The first author sent the result of this selective coding process to all authors and received feedback. This process took months in order to come to a structure that was satisfying to all involved in the analysis process. The result of this inductive analysis process forms the content for this article.

Results

In this section, we present the results of the analytical process, which sought answers to our research question: What themes, problems, and processes are observed in the process of a researcher duo (one researcher with academic background and one with disability experience) working together in a long-term and intense collaboration on an inclusive research project (WTLT) within which they have developed, organised, and delivered training to inclusive research projects in the Netherlands.

Through the collaborative analysis process, we inductively derived a manageable structure of six significant themes:

1. Belonging
2. Self-awareness and competence-building
3. Communication
4. Sharing power
5. Time
6. Vulnerability

Although we reached consensus that data cohered together meaningfully within these themes, and we agreed that there was a clear distinction between themes (Braun & Clarke, 2006), we also noticed links between themes. These links will be elaborated in the Discussion section.

In the Results section, we embed extracts of raw data from fieldnotes/diaries, blogs, and vlogs to illustrate the complex story captured in the data, in order to do more justice to the richness of the data rather than providing only a flat description (Braun & Clarke, 2006).

Theme 1: Belonging

In their personal research diaries, the researcher duo frequently opens up on the theme of belonging and how this is impeded because of prejudices and (self-)stigma. As Researcher 2 told a journalist:

> *"At a certain point, you accept that society is like that. I don't know any better than people looking at me or staring at me. I know it happens, although I can't see it because of my visual disability. But my researcher colleague notices and gets angry about it."*
> *(Lingbeek, 2017)*

The theme of prejudice and (self)stigma was often elaborated upon as an important barrier for belonging in research and in society, something that stands in the way of equal cooperation. On this theme, researcher 1 and 2 wrote respectively in their diaries:

> *"People speak to my colleague with a high [pitched] voice. Sometimes people speak to me and ignore her. My colleague says she is used to this… She wonders about me getting upset by this."*
> *"This research is very confusing to me. My whole life people say to me that I don't know anything. And now my research colleagues actually do value what I know and tell me that I should take more initiative. That they don't have the answers either. When I think about this, I experience it as a compliment. But it is confusing nonetheless."*

While meeting other inclusive research teams, the researcher duo witnessed hierarchy-based dynamics. They saw people struggle to not be seen as the most disabled one in the room. The researcher duo observed people debating about who was the best expert by experience, which is illustrated by this quote from the diary of Researcher 1:

> *"We witnessed discussion and quarrels today between experts by experience on who is the best researcher? They concur about who is the most attributed and able to contribute to the research. This battle reveals – I think – their hard work to belong to the research project, doing their ultimate best to succeed."*

The researcher duo talked about this experience. They learned for their own collaboration how important it can be to organise reflection and dialogue on (changing) responsibilities, leaving the research project, quitting, and taking up less or more work. This should not

occur in a way where one person feels disrespected or that their work is not valued, but both should feel that they can share ambitions or place limits, and can decide for themselves whether to (temporarily) quit or continue.

We connect these results with the concept of belonging, referring to the definition of inclusion that means not only 'taking part', but also having rights and responsibilities as a legitimate member of a group (Van de Putte et al., 2018). A group can exist at different levels, from the macro level (society as a whole) to at the micro level (in this case a research group): people may (not) feel part of 'regular' society and/or might (not) experience belonging within the research group.

Theme 2: Self-awareness and competence-building

Working as a researcher duo, self-awareness and competence-building for each of us was catalysed. Researcher 1 wrote in her diary about her encounter with her colleague, Researcher 2. In this encounter Researcher 2 explains that while working in the research context, she becomes aware she is more than 'a disabled person' and that she doesn't want to narrow her work down, solely to the disability experience:

> *"My colleague told me today she doesn't like the idea of working for a self-advocacy movement run by people with ID anymore. She started feeling uncomfortable because – in her job – each time she has to introduce herself as a person with ID."*

Acknowledging and valuing differences in perspectives, experience, and knowledge come forward as vital elements in inclusive research. At the same time, lack of education is reported by the researcher with disability experience as a burden and frustration. The following quote from Researcher 2's diary discusses being excluded from regular education because of her disabilities and being involved now in inclusive research which allows her to learn on the job and to develop talents and skills:

> *"I am not happy with the education I had. I wished I had gone to an inclusive school. I never had the opportunity to do the studies I aspired to. Now I am happy with the opportunity to learn on the job and to contribute to research."*

Theme 3: Communication

To be able to all join the research work, sometimes other methods of communication need to be sought and/or created. In their search for ways to communicate, the researcher duo searched for ways to facilitate the collaboration in terms of communication taking into account the visual impairment of Researcher 2. One example was depicted in a diary quote by Researcher 2:

"From the introductory meetings we have included our notes in a Prezi presentation (prezi.com). (…) This helps me a lot., because I have a visual impairment. (…) We have an overview of the meeting (…) And at the same time, I am able to zoom in on one section of the presentation."

Collaboration with visual artists, photographers, and filmmakers was found to be an indispensable condition for the researcher duo, as illustrated in a blog written by Researcher 2 about a film the researcher duo created together with filmmakers to introduce their research work to a diverse public (see also: Picture 1, a still from this film):

"In this film two tough women are driving a Cabrio. The film has the appearance that they get the job done together and are on the road together for this. Under all circumstances! And we do that too... My colleague and I. Before we made the film, we looked for what connects us: we love good music, travel, the feeling of freedom... and in the Cabrio it all comes together."
(Sandvoort, 2017)

We could show this film to students, to professionals, to researchers, to experts by experience and, their families. They all could grasp the essence of our message: we try to collaborate, and that's interesting, sometimes difficult, and always far away from the pity discourse.
Learning from these experiences, the researcher duo will create a new film revealing what they have learned from their research work rather than an 'EasyRead' article. We believe that this makes the research results more widely accessible: no reading skills or large investment in time, energy, and focus is needed.

Theme 4: Sharing power

The theme of power in the research work focuses on how decisions are made, who is in control, and who has influence on the research process.

The researcher duo learned that in every phase of the research work they had to keep searching for their (changing) roles and responsibilities. The quote below goes back to the start of the WTLT research project. Researcher 2 asked Researcher 1 for 'the next step.' Researcher 1 wrote in her diary:

"It was as if Henriëtte asks me to give her the answers.
And I don't have them.
It is as if she asks me to give her homework.
This is not how I want to work together."

This incident was crucial for the collaboration of the researcher duo. Long talks and many hours of collaborative reflection were needed to work this out for both of the researchers. Both researchers feel like they keep on profiting from this incident. The academic researcher said: *"I don't know"*, and this brought confusion, but also room for the researcher with disability experience to take more power and control.
Every research project starts with decisions about the focus of the research question and the design of the research. In our research project, Researcher 2 had a decisive role in this phase. She contributed to setting the research agenda, designing the research process, and deciding where the money goes. In her diary, Researcher 1 wrote the following on fostering shared power and ownership in inclusive research:

> *"If we want researchers to design and write projects in co-creation with experts by experience, grant-giving organisation will need to provide the necessary time to co-create and co-write. The grant-giving organisations will also have to acknowledge that predictions on methods used and timeline are more difficult to make if you collaborate with experts by experience. Some extra space for adjusting time and method to the needs of the team will be appropriate."*

Ownership of the research and the research question was of major importance in the collaboration in the researcher duo. Both researchers were eager to realise the goals of the research work. This helped during their four years of intense collaboration.

Theme 5: Time

This theme is strongly intertwined with all the other themes, but proved to be an important condition in itself. We include a quote from the diary of Researcher 1 written after she met Researcher 2 for the first time:

> *"Our first date took place in my house. After a long day talking and getting to know each other, my new colleague says to me: "I know what you need. You need structure. And I am able to give you this." I smiled. Ouch. She already recognises something that is so true. Structure is what I need. And I need somebody else to help me create it…"*

Having enough time to get to know each other surfaced as a major issue during our research. The duration of the research project can catalyse ownership of the project and ambitions to evoke positive change through research. The researcher duo shared thoughts on the cruciality of creating enough time: to get to know each other, to discover what the other needs, and to take up roles in the project that fit the temperament, competences, and ambitions of the researchers.

Theme 6: Vulnerability

When the researcher duo started delivering training to inclusive teams, they reported feeling insecure. They had many questions about how to enter these teams and how to position themselves. As Researcher 1 wrote:

"We felt being watched. We had to be good;
we felt like we were not allowed to make any mistakes."

However, this changed over time:

"Now we feel more relaxed in the cooperation: the cramp disappeared.
Vulnerability is an important issue: can we be vulnerable;
can we make mistakes and learn from them?,"

she wrote later. The researcher duo struggled in the beginning of *their collaboration with mutual engagement in dialogue. Researcher admitted in her field notes that she was used to taking care of people with disabilities, instead of working with them as colleagues, giving feedback and sharing thoughts. This is illustrated in the next quote from her diary:*

"How must I share my thoughts with Henriëtte?
How can I bring in my questions, insecurities, and delicate thoughts on our
collaboration? I am afraid to hurt her feelings."

The researcher duo learned that admitting to themselves and others that they were constantly struggling and searching was very helpful in their collaboration. This process brought relief and tranquillity to their relationship and their research work.

Conclusion

What themes, problems, and processes are observed in the process of a researcher duo (one researcher with academic background and one with disability experience) working together in a long-term and intense collaboration on an inclusive research project (WTLT) within which they have developed, organised, and delivered training to inclusive research projects in the Netherlands. This is the research question we explored in the forlaying study.

Our findings indicate that reasons to conduct inclusive research are clear and defendable, but necessary conditions include (1) experiencing belonging within the research group, (2) empowering people in a team through growing self-awareness and competence-building, (3) room for reflection and searching for various ways of communication, (4) sharing power and ownership of research process, (5) enough time to foster the above conditions, and (6) mutual engagement in accommodating vulnerability in dialogue and collaborative work.

Discussion

The section concludes with the limitations of this research and its implications for practice and policy in promoting inclusion, with suggestions for future research.

Limitations

We recognise the limitations of analysis based upon the experience of one researcher duo in the Netherlands. Nevertheless, we do believe we have identified some critical contextual factors crucial for inclusive research and for collaboration within teams.

Implications

In our research, it became clear that if people with disabilities and their colleagues become aware of their knowledge, their power, and the danger posed to their collaboration by (self-)stigma (Scior et al., 2015), something changes in their lives and in their collaborations. The researcher duo started their work together with a binary vision, juxtaposing the researcher with academic background and the researcher with disability experience. On the road they discovered how entangled their lives are, how the researcher with disability experience became a researcher with academic skills herself, and how the researcher with academic background came to reflect more on her own life story and experience.

For all research members to be able to flourish and to develop talents, a diversity-sensitive context (MacDonnell & MacDonald, 2011; Peels & Sergeant, 2018) must be created, with training and coaching provided as needed. Support, protection, and presuming and supporting competences of all the members of inclusive research teams are evaluated as very important pre-conditions for inclusive research (Strnadová et al., 2014; Embregts et al., 2018).

An overarching theme in our findings is related to stigma. Scior et al., (2015, p. 15) define stigma as *"the co-occurrence of these stigma components: labelling, stereotyping (that is negative evaluation of a label), prejudice (that is endorsement of negative stereotypes), which lead to status loss and discrimination for the stigmatised individual or group."*

During their intense collaboration in which the researchers did (almost) do everything together, the researcher duo became aware of the impact of prejudice, (self-)stigma, and (their own) binary thinking, which influences not only the position of people with disabilities in our society, but also their role in research. The label of intellectual disability can cause low self-esteem (self-stigma), lower expectations in society, and being positioned lower on the research participation ladder (Arnstein, 1969; Tritter & McCallum, 2006; Kliewer et al., 2015).

Our research data reveals that it's not about more participation always being better, it is about 'meaningful participation' in which all participants are convinced on the importance of the contribution of all involved and on the worth of the knowledge of each other in the team (Budge et al., 2016). This means people are not participating for tokenistic reasons but for intrinsic arguments, for bringing in more diversity, quality, and richness of research process and (dissemination of) products. This means time for reflection on inclusive collaboration is crucial (Johnson & Johnson, 2009; Bigby et al., 2014; Strnadová et al., 2014): open and sincere dialogue and reflection helps greatly, and can form a solid basis for daily work. Our data shows the importance of collaborative reflection on the meaning of disability, on what people need within a research collaboration, and on the experience and impact of prejudice and (self-)stigma during inclusive work processes. It is only possible to discuss this if there is time for slow research, if there is shared history, and reciprocal trust. Attention must be also paid to matching talents and tasks in the research process (Nind, 2014; Embregts et al., 2018).

Future research

The authors recommend further research into how inclusive research in a disability-focused context and the conditions associated with its success can be a catalyst beyond research that is inclusive of disabled people, leading towards a less hierarchical academic world and a more supportive, democratic, and safe space for researchers.

Currently, many organisations provide funding on the condition that lead researchers work closely together with experts by experience. Tokenism can still lurk within such constructions, along with the risk of 'data robbery': stealing the stories shared by experts by experience without acknowledging their ownership (Nierse & Abma, 2011; Nind, 2014; Embregts et al., 2018). The authors recommend further research to gain insight into what conditions must be met to ensure that this is a promising evolution.

People with intellectual disabilities and people with mental health problems are often seen as the lowest in the disability hierarchy (Deal, 2003; Scior & Werner, 2016). This hierarchy perpetuates the notion that some disabilities are more acceptable than others in our culture. This hierarchy can be internalised and deployed by people with disabilities, as well as by those without. From the data, we observe that the disability hierarchy appears to be a barrier to inclusive research. Future research is needed to get deeper insight in these processes.

To conclude, our research reveals two results that can be framed as a 'true contradiction' (Rieger & Young, 2019): (1) Inclusive research needs well-prepared diversity-sensitive research environment and (2) at the same time *"fear of doing it badly should not prevent us from attempting it"* (Sin and Fong, 2010, p.21). Struggle is central in inclusive research,

and therefore we believe we are all responsible for welcoming this experience of negotiation and transformation, and discovering what Melanie Nind (2014, p. 84) means by *"the full potential of inclusive research."*

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2.3. The researcher duo presents – 'The Cabriotraining'

"Sofie Sergeant and I made a movie at the beginning of our research in an open-top convertible (Cabrio). This took place in the port of Rotterdam. The title of this film is: 'Two researchers on the deep blue sea'. With this film we want to portray our research in a 'cool', positive and powerful way."
(Sandvoort, 2019, September)

Henriëtte points at a crucial issue in this quote from her column. We also created this film in a *"cool, positive and powerful way"* because we wanted to stay far away of the paternalistic discourse of disability, care and protection. We wanted to put focus on the collaboration of two people, each with own knowledge and experience to share.

Figure 15b: Still 2 from Film *Two Researchers* © Iris Cuppen

The name Cabriotraining originated during the making of our film. The word Cabrio consists of six letters. After writing up the 'On the road' article, it was Henriëttes idea to connect the themes we found – through the joint inductive analysis process – to each letter of CABRIO. This creative matching debouches into the following (Sandvoort, 2019, April):

Contact and communication

This provides oxygen to any collaboration. If we work with people with disabilities, we will also have to leave 'the verbal box'.

All the way inclusive

How can we create room for co-creation not only in the data-collecting, analysing and disseminating but also in the setting of the research agenda.

Belonging

Belonging in research is about having a meaningful job, being able to contribute, being able to contribute to changes. This gives someone the feeling of being valuable.

Rest and time

You should take the rest and time to get to know each other before diving into the research with each other. This requires adjustments from both sides.

Interest in each other's skills

Knowing who you are and what you can do in research is an important condition in order to contribute and collaborate.

O stands for okay: you can make mistakes

This is perhaps the most difficult condition for inclusive research. Everyone is vulnerable: this connects us as people. It is important to radiate this within your team because it promotes equality between people with and without disabilities.

2.4. References

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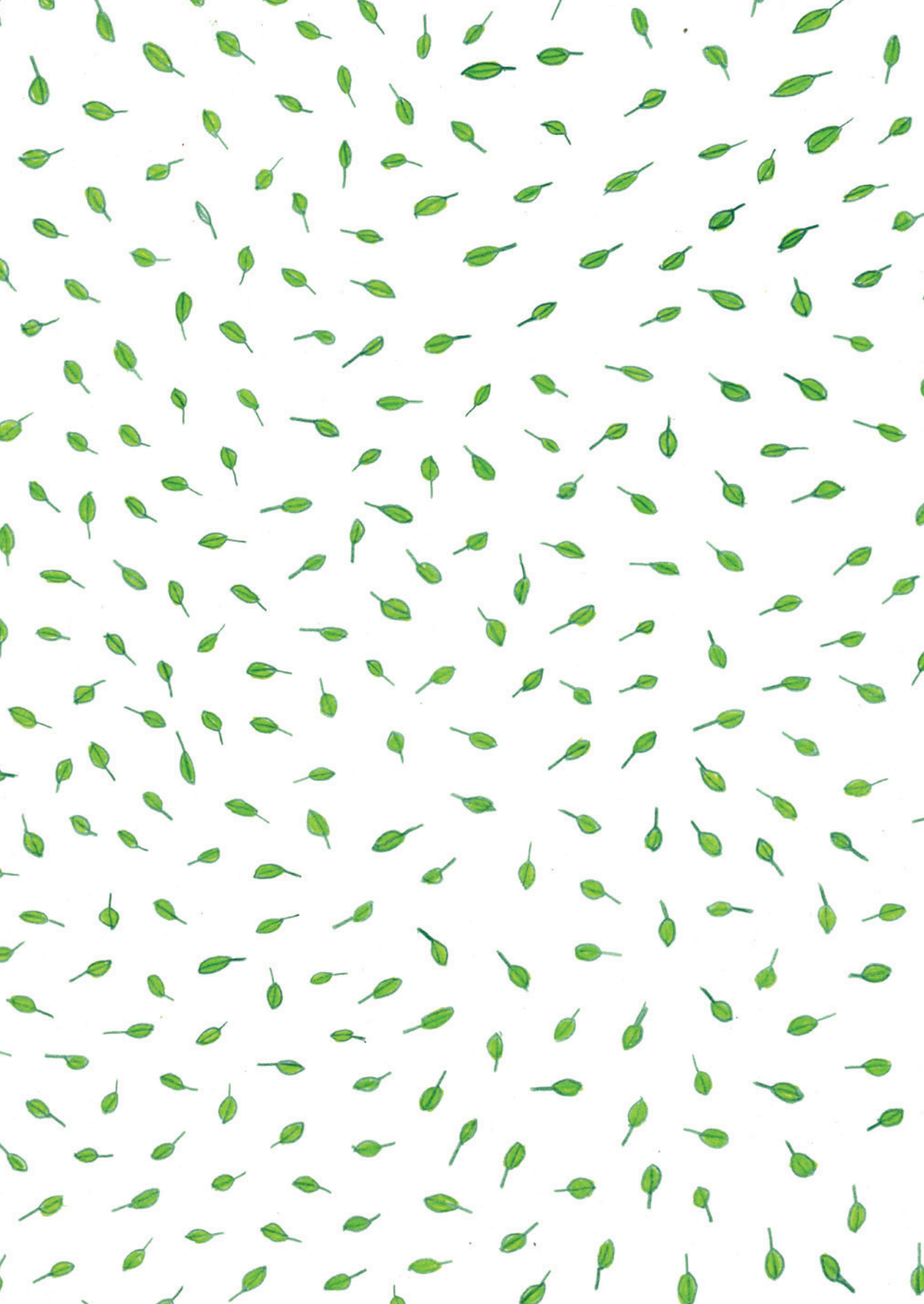


Chapter 3 – Creative research methods

This chapter is based on:

Peels, H. & Sergeant, S. (2018). Painting Pictures: Towards connecting through imagery in dialogues with young people with intellectual disability. International Journal of Child, Youth and Family Studies, 9(4), 125-145. DOI: 10.18357/ijcyfs94201818644 120-

Sergeant, S., Peels, H., Schippers, A., Joosa, E., Brown, R. & Van Hove, G. (2021). Reflections on the results of a roundtable on creative methods in disability research. Murmurations: Journal of Transformative Systemic Practice. 3 (2). 128. DOI: 10.28963/3.2.9.

In this chapter we cruise through all the stages of the sushi, aiming to discover how to broaden the comfort zones of us – academic researchers – seeking for more alternative, creative and nonverbal research and communication methods.

In both the chapter 3 articles Hanna Peels and I "contributed equally and are therefore considered as first authors". With adding this sentence in both articles, we explicitly illuminate the worth of the collaboration and joint work.

3.1. Introduction: 'stepping out of the verbal box'

Engaging in inclusive research ourselves and developing training for other inclusive research projects by times felt messy and risky. I have done much reading to feel more connected to colleagues worldwide engaging in inclusive research.
I searched for diverse, multi-sensory and accessible materials working upon the principles of Universal Design for Research (Williams & Moore, 2011). I collected all the links to articles, books, film, music, story and cartoons and placed them on the website of our foundation 'Disability Studies in Nederland'[3].

Figure 16: Mixed Forest

[3] https://disabilitystudies.nl

On this website I created – together with artist Saar De Buysere, cartoonist René Krewinkel and many other experts of different fields – a 'mixed forest'[4] with many different trees. Scanning Figure 16 gives immediate access to this Mixed Forest.

Each tree stands for a theme connected to the disability studies field.

One tree is on inclusive research and participatory research methods: the spruce[5].

Figure 17a: Spruce: The tree on inclusive research and participatory research methods © Saar De Buysere

The spruce is the evergreen tree that is adorned in our culture around Christmas indoors or outdoors with baubles, garlands, lights, spikes and angel hair. We use the image of the spruce in the theme of 'participatory research methods' because 'the Christmas tree' is THE tree that invites to collaborate. And this collaboration sometimes goes very smoothly and easily, but we all know the discussions about taste, colour and kitsch when decorating the Christmas tree. Decorating together sometimes leads to annoying or hilarious scenes in which fumbling, searching, untangling, laughing ... are more common than weft.
Thanks to the support of a lot of colleagues from different fields, I decorated this tree with all kinds of materials that explain and reflect on different matters of inclusive

[4] https://disabilitystudies.nl/les-en-studiemateriaal

[5] https://disabilitystudies.nl/participatieve-onderzoeksmethoden

research. In our first meetings with (inclusive) research teams I shared this site, allowing many others to profit from our collection.

Apart from this tree on inclusive research (see Figure 17a) – together with many experts – I created more trees, loading them with diverse content, within a 'Mixed Forest'.

In making these themes accessible for a wide range of people, I needed to cooperate with artists and include painting, music, theatre, film, photography in order to enrich the findings in scientific literature.

René Krewinkel created a cartoon based upon the trees drawn by artist Saar De Buysere. In Figure 17b, the cartoon on collaboration in inclusive research is depicted.

Figure 17b: Cartoon on collaboration in inclusive research © René Krewinkel

This work and the results of our first article 'On the road' made it clear that this dissertation needs to also dive into the importance of contact and communication, to deal with the barrier of literacy as Nind and Vinha put it (2014, p.40, see also 1.2. in my dissertation). Although people can be limited in verbal skills or have no written literacy, they have no less of an inner world than others. How to make connection to the inner world is therefore an important question which we explore in the second article 'Painting Pictures'.

3.2. Prelude to 'Painting Pictures'

Colleague Hanna Peels is also working on a PhD and committed in inclusive research herself. Hanna and I engaged in a reflection on co-occurring changes in Dutch society, the nature of caregiving and the increasing appeals for empowerment for and by people with intellectual disabilities. We use the method of a critical dialogue to analyse our experiences in previous research and the possibilities imagery harbours to improve dialogues on existential themes. In the article Hanna Peels departs from her experience with analysing blogs written by a researcher with experiential knowledge Beau. Alongside, I depart from my experiences in previous research with the Drawing Lab (Sergeant & Verreyt, 2016), an inviting environment in which participants are first asked to make a drawing (graphical elicitation) and second to share verbally on their drawings. The forms of imagery used in our respective research differs but our experiences with using imagery in research were very similar and – after analysis of the critical dialogue – condensed in five themes: leitmotiv, ambiguity, choice, revelation and distance.

Note: Hanna Peels works together with Beau. Beau is a pseudonym, a fictitious name Beau chose herself. As a disabled woman she searched for a positive name expressing beauty and strongness. I asked her ones if she did not want to add a surname. She declined this proposal adding that 'Beau' does not need additional surname.

3.3. Painting Pictures: towards connecting through imagery in dialogues

Abstract

The authors discuss pivotal themes in the use of imagery (visual and verbal) as a method to engage in dialogue with young people with intellectual disability (ID). In their discussion they reflect on co-occurring changes in Dutch society, the nature of caregiving, and the increasing appeals for empowerment for and by people with ID. A critical dialogue is used to analyse experiences with imagery from their previous research, and the possibilities imagery harbours to improve dialogues on quality of life with young people with ID. Through analysis of the critical dialogue, five themes were identified: leitmotiv, ambiguity, choice, revelation, and distance. To conclude, the authors discuss why family members and professional support workers should consider using imagery as a productive methodology.

Introduction

"A new Soap Bubble Syndrome has been born, a beautiful dream bursts with an unmistakable bang and consequently takes itself out. At that point I often cannot but lament that when I do not imagine, I will not be anything."[6]

(Beau, 2010b, sentences 15-16)

The metaphoric language of Beau, written in an online blog about living with disabilities, provides vivid examples of imagery. Imagery in any form elicits an instant connection between people that evokes the need for interpretation. The power of imagery, or the ability to narrate with images in different modalities, has been well explored through visual images (Stanczak, 2007; Wang, Yi, Tao, & Caravano, 1998), music (Howe, Jensen-Moulton, Lerner, & Straus, 2015), verbal narratives and metaphors (Stefán, 2010; Dunn & Burcaw, 2013), dance (Hermans, 2016), and other means. Less research has been conducted on the role of imagery in discussions about existential topics, such as life, meaning, purpose, and the future, between young people with intellectual disabilities and their friends, their families, and professionals. However, discussion of these topics is essential to shape support for young people with ID and to improve their quality of life (QOL), especially in domains such as emotional well-being, interpersonal relations, and selfdetermination (IASSIDD SIRG-QOL, 2000). All people, with or without ID, think about their lives and what they want in life. Atkinson (2005) stated that, *"Life stories, and the opportunity to tell them, are particularly important for people with learning disabilities because often they have been silent, or silenced, while other people — families, practitioners, historians — have spoken on their behalf."* (p. 7). The opportunity to tell life stories, and discuss them with other people, is an opportunity that does not always come naturally for young people with ID. Although family members and professionals may presume that they have a fairly good view of what is going on in a young person's life, the use of imagery in discussing life stories can be a surprisingly revealing and confronting method for challenging these presumptions. Using imagery as a method to discover new information (as with the use of blogs, diaries, photo-elicitation, photovoice, etc.) forces the other in the dialogue to relate to the distinctly different position that the young person with ID may have in life, and his or her personal interpretation of life events.
The objectives of this study were to:

1. Sketch the (Dutch) context within which the need for an existential dialogue with young people with ID emerges;
2. Explore the power and possibilities of using imagery in research and dialogue by means of a critical dialogue between the researchers; and

[6] Beau granted permission to use excerpts (translated from Dutch to English) from her blog in this article. The translation was done by one of the authors in consultation with Beau; the translated excerpts were presented to Beau before using in this article.

3. Give practical directions for family and support workers to create an environment in which imagery can be used as a method to engage in dialogue.

Background

Changing Landscape of Care and Support Strategies

Working with young people with ID in the Netherlands has changed drastically from the starting point of charitas [charity]. For centuries, medical care has been at the very core of support for Dutch people with disabilities. Since in this model the person with disabilities was seen as a 'victim' of the disability, the focus of support was to find a cure. Since the 1960s, a new socialecological perspective on disability has gradually emerged in the Netherlands, following the rise of advocacy movements in America, the Netherlands, and elsewhere, and developments in disability studies. This perspective no longer classifies disability as a trait of the person involved, but as a concept that is constructed and influenced by the society in which the person lives (Brants, van Trigt, & Schippers, 2016; Hoppe, 2012). The social-ecological perspective prompts professionals to develop new support strategies for young people with ID based on concepts of reciprocity and equivalence. People with ID are seen as experts by experience: they have useful knowledge to share (De Waele, van Loon, Van Hove, & Schalock, 2005). Ideally, professionals and caregivers are no longer in the decision-making position when it comes to support; the Dutch (and global) advocacy movement of people with ID has made clear that they have a basic human right to be in charge when it comes to their lives.

High Demands in Society

In the Netherlands, being able to participate without support is more challenging now than in past decades, due to the fast pace of societal development and high societal demands on citizens. This development has been reported by the Dutch National Institute for Health Services Research (NIVEL) in a 2015 report (Speet & Rijken, 2005), and similar concerns were raised by Dowse (2009). In public debates there is much discussion of taking control of one's life. Even in these ideologically driven debates, there is an overtone that tacit expectations should be met by people with ID and their caregivers: despite their apparent disabilities, they should be obliged to meet the participatory requirements of a rapidly changing society — and their family members should feel equally obliged to support them in this participation. The fastidiousness of society therefore places a huge pressure on young people with ID and their families to transcend their disabilities, to (be able to) participate. However, as the Dutch national self-advocacy group for people with intellectual disabilities (the LFB) notes, while there may be ample opportunities for inclusion, the tacit views of other people in society, especially professionals, hinder inclusion (Speet & Rijken, 2005).

Disability and Communication

For young people with ID, difficulty with producing and understanding more complex language can lead to friction with family, friends, and professionals (Lewis, Gaffney, & Wilson, 2016). Therefore, much emphasis in the Dutch context of support is placed on training individuals to acquire a functional level of verbal language. In the light of recent insights into Universal Design (Null, 2013) and Universal Design for Learning (Nelson, 2014), this emphasis on functional verbal communication falls short when it comes to dialogues about the meaning of life, achieving a sense of belonging, and discussing QOL issues. Even though people in the field recognise the potential of approaching these themes using tools that are better suited for the communication abilities and styles of people with ID, the application of new ways of communication in daily practice still seems to be uncommon (Williams, 2011). In the field of working with people with disabilities, most instruments or programmes that address a thorough conversation with the individual with ID seem to be focused on producing an outcome that will give the family or professional practical tools to shape support for the young person.

These programmes and instruments are certainly useful, but they fall short of building a true bridge between youngsters with ID and their dialogue partners (Sergeant & Verreyt, 2016). A clear example is the use of pictograms, which are used to support both receptive and expressive communication of people with ID. However, the use of pictograms often focuses on the context of instrumental communication — communicative interactions aimed at gaining certain objectives, or facilitating certain activities or interactions. Therefore, the way pictograms are currently used constrains the potential communicative power of the images to a certain extent. Even if images are used to communicate about emotions, they are mostly used in an instrumental way; for example, to express anxiety or sadness. In the Netherlands, fewer examples are seen where images are used to explore the deepest feelings, meanings, and sense of being of the other: the so-called narrative of life. The assumption that meaningful communication with young people with ID can (or even should) be simplified to unidirectional choices reflects a tacit underlying idea about the abilities of young people with ID, including their ability to engage in complex, diverse, and reflective dialogues.

Method

The authors of this article have years of experience working in services for people with ID. They have seen on a daily basis the importance of using various forms of communication to connect to people with ID — or people without ID, for that matter. Starting from this position of engagement, both authors are involved in participatory research with people with ID. Sofie Sergeant has been conducting participatory action research. One of the

methods she developed is called Tekenlab [Drawing Lab], an inviting environment in which participants (with or without ID) are asked to make a drawing and share their reflections and stories about one of the domains of QOL linked to their personal life (Sergeant & Verreyt, 2016). Hanna Peels has been exploring the role of people with disabilities in the care system as experienced by people with ID. Her method has consisted of analysing in various ways a blog about the care and health system in the Netherlands in cooperation with 'Beau', its author. Beau blogs about her own experiences and thoughts on living in a facility for people with physical or intellectual disabilities. In her blog entries, she often uses metaphors and poems to describe emotionally charged experiences.

The authors noticed that even though the forms of imagery used in their respective research differ, their experiences with using imagery in research were similar: the advantages of using imagery seemingly transcend the form. The decision was therefore made to explore these advantages by critically questioning each other through the method of a critical dialogue. Karlsson (2001) described the critical dialogue as a process *"where the individual examines and verifies his/her own and others' perspectives and assumptions"* (p. 225); he also stated that *"the discourse of dialogue is an exchange of ideas and meanings, and the purpose is of learning more than judging"* (p. 212). The dialogue in this research was critical in nature, given that the authors not only discussed their research cases but endeavoured to come to a closer understanding of each other's research. By engaging in dialogue, the authors compared their respective research (Drawing Lab and blog analysis) as if each of their research projects was a separate 'case'. In comparing these cases, the authors discussed their own experiences, values, and learning moments in their research. Within the framework of critical dialogue, a general inductive approach (Thomas, 2006) was used to develop a framework for the underlying structure and experiences evident in both cases, and in the dialogue about the cases. The researchers questioned themselves critically on their choice of method, the similarities and differences between critical incidents, the impact their research has had on themselves as researchers, and the way the use of imagery helped and inspired the researchers in their research. Important and recurring key concepts in the dialogue were clustered. This led to five main themes that will be discussed in Findings.

Comparing cases offered each researcher the chance to reflect on her own research as well as evaluating the other's. Following Smaling (2008), the authors kept reminding themselves of the reflexive and analytic nature of their dialogue, and therefore secured empathic cooperation while discussing different insights or arguments. This emphasis on the reflexive nature of the dialogue was an essential step towards using the dialogue in a transformative way. Following Freire (2005) the authors entered the critical dialogue fully aware that their thoughts and ideas would be changed in comparing the cases. Rooted in

participative action research, the researchers aim was in fact to change the care and support offered to young people with ID, as well as to improve the ways that researchers can make young people with ID feel welcome to participate in research.

The authors shaped the critical dialogue by using materials gathered into journals they kept during their own research: critical incidents, key quotes, and field notes. To paint a picture of the research that led to the reflexive process described in this article, the authors use quotes and vignettes from their ongoing research. Their joint reflexive process, however, provides the framework for this article.

Target Group

The critical dialogue revolved around communication with young people with ID. Like Goodley and Runswick-Cole (2014), the authors acknowledge that many people labelled as having ID prefer no labels whatsoever. The term intellectual disability (ID) is used here because it is a common term applied across the globe. In this article, the term 'young people' refers to persons between the ages of 15 and 24, following the definition of 'youth' given by the United Nations Department of Economic and Social Affairs (n.d.). Young people were chosen as the target group in the critical dialogue because this is an age range during which people experience the transition from childhood to adulthood. This transition is accompanied by existential questions and doubts about, for example, identity, place in society, work life, and relationships.

Ethics

Informed consent was obtained from all participants in both the Drawing Lab research and the blog-analysis research, following the Disability Studies Netherlands Code of Practice for researchers 2016-2017 (DSiN, 2016). Beau granted permission to use excerpts (translated from Dutch to English) from her blog in this article.

Results

"We metaphorize, therefore we know.
Metaphors are primary in relation to our existence as we know it."
(Dolmage, 2005, p. 110)

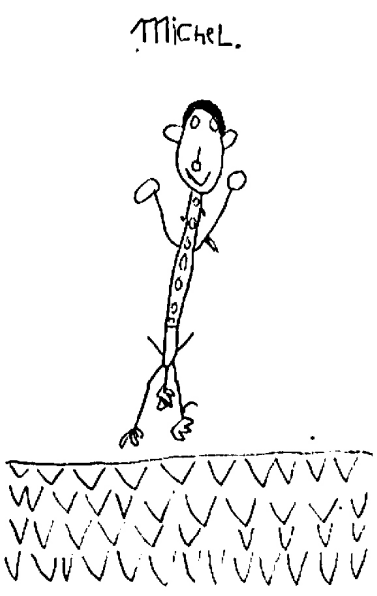
Both family members and caregivers often search for a useful method to guide discussions about existential questions with young people with ID. The authors' own experiences as both professionals and researchers led them to conclude that imagery offers an attractive, rich, and engaging way of connecting. In their critical dialogue, their communication experiences were discussed, leading to the identification of five themes that apply to both verbal and visual imagery: leitmotiv, ambiguity, choice, revelations, and distance. These

five themes reveal the possibilities and strengths of using imagery as a means of communicating with young people with ID.

In presenting these findings, the power of using visual images in engaging in dialogue is disentangled from, and juxtaposed with, that of using metaphors. The argumentative nature of the critical dialogue (Smaling, 2008) is reflected in the structure of the results: each discussion of one of the five themes will start with exploration of the theme in visual images, metaphors, or verbally painted pictures, and conclude with some experiences and thoughts. Vignettes and quotes from previous research are added to illuminate the findings.

Leitmotiv

The term 'leitmotiv' has its origins in music and refers to *"the recurring musical themes ... attached to characters, objects, situations, and ideas ... underlying the Wagnerian Gesamtkunstwerk"* (Scher, 2004, p. 185). In discussing imagery the authors found that a coherent cluster of important values and convictions resurfaces each time a meaningful dialogue takes place. The entirety of thoughts, needs, and dreams that a person wants to discuss is similar to a leitmotiv in music. The leitmotiv assures both partners in the dialogue that there is no need to push their agenda forward; the agenda will not disappear, but is there to revisit when needed.



The person who drew this image was not a good talker. He could only say a few words regarding this image. In the few words he spoke to us, he said, *"I am a man. My penis is very important to me. I am a man. Look at my penis. I am beautiful. I want to take care of my body. Washing and shaving is important. I am a man. My body is important."* He said this while looking very happily and proudly at his drawing. The team learned more about him, without having to ask him who he was and without asking things about 'physical well-being' on an abstract level. His leitmotiv showed up through the image. A support worker came to the team members, looked at the image, and smiled: *"Michel is a man"*, she said, *"and that is the starting point for all our interventions or support."*

Figure 18: Vignette: Leitmotiv

The maker of an image has his or her own agenda, a theme or a message to communicate. When confronted with an image, one may choose to follow that agenda, or find a way to avoid it. The image is central to a personal story, and the interpreter is the director of that story. The reader animates and re-animates the storyline and decides how to interpret it. *"Metaphors might be seen as bridges on the verbal map. Indeed, the Greek root of the word, metapherein, means 'to carry across' "* (Dolmage, 2005, p. 109). Stories are by definition useful in bridging the experiences of different people. Metaphors and stories are often rooted in joint experiences. Using shared language has the power to bring together family, support workers, and young people with ID.

Surpassing the practical use and intention of metaphors in support work is the observation that the use of metaphors is close to the heart and nearly unconscious: *"But metaphors are never disinterested. The author submits that there is more going on than just words when metaphors are used. In other words, the argument is that despite our nearly unconscious reception of them, metaphors carry and construct particular social and cultural meanings"* (Dolmage, 2005, p. 111).

Consciously or unconsciously, partners in a dialogue look for the agenda of the other while interpreting the product of imagery. Using imagery offers the opportunity to talk about the desired outcome without directly addressing or questioning the truthfulness of the interpretation or agenda of the other. Moreover, since the intended agenda is secured in an object (visual image or metaphor), the important themes for the young person with ID will reappear when needed.

The leitmotiv is an important concept for the simple reason that young people with ID, and their families, live with challenging circumstances. This starts from the moment of diagnosis and the beginning of treatment to the experience of an impressive number of professionals entering and leaving their lives. Being able to grasp important themes and to have the certainty that they reappear when needed is a vital part of expressing oneself as a person growing up. Moreover, the leitmotiv ensures an ongoing dialogue between the young person with ID and family members or support workers.

Looking at her drawing, the woman in the Drawing Lab talked to the team about the importance of the sun, and warmth in her life. She loved the sun on her skin; she enjoyed walking and wandering through nature. The researcher interpreted the drawing as a person and a house. However, the woman said, *"On the right I drew a baby in a pram".* The person in the drawing turned out to be a flower. The woman explained about her dream of having her own baby, and the possibility of not being able to reach this dream.

After looking at the picture again, she started talking about the children in her family, of being an aunt and enjoying this role. In the dialogue she gave several meanings and interpretations of this image of the baby in the pram. Her story, and the initial interpretation of the researcher, illustrates the possibility of ambiguously interpreting and reinterpreting the meaning of a drawing and discovering stories hidden in it.

Figure 19: Vignette: Ambiguity

Ambiguity

An image may be seen as an inventory of multiple meanings. *"Rather than demanding only an objective reading, images also elicit various subjectivities from our participants that – instead of being bracketed away – can be probed and analysed"* (Stanczak, 2007, p. 7). The meaning of an image is neither steady nor stable. Depending on who a person is,

and how one looks at the image, one discovers other things and stories: *"Images trigger different insights, depending on the different questions that we ask of them"* (Stanczak, 2007, p. 9). Meaning is given from one's own life events, experiences, and prior knowledge. By exploring a drawing, and by drawing further together, more can be discovered with regard to people's own assumptions or autonomous expression (Sergeant & Verreyt, 2016). In this way images – unconsciously – force us all to retreat to our own interior worlds and to personal stories. A story, read or told, will evoke different 'verbal images' in the mind of a reader or listener. Like visual images, the verbal image is coloured by one's life's experiences: *"A simple way to summarize this point would be to say that we understand metaphors because we share experiences, and we come to experience the world a certain way as a result of how we metaphorize it".* (Dolmage, 2005, p. 111). In imagery there is the opportunity to highlight or hide parts of the story that do not suit the author (Robertson, 1996; Dunn & Burcaw, 2013).

Underhill (2011, p. 26) pointed to the fact that metaphors are not only based on one's personal experiences, but on shared experiences as well: *"In a word, metaphors are embedded in networks of underlying conceptual equations".* In this shared experience, however, lies ambiguity: unspoken suppositions about the experiences of the other may colour our interpretation of the metaphor or verbal image the other one uses. Family members are often more familiar with the experiences of a youngster with ID than professional support workers are, yet both should be aware of the dangers of making presumptions regarding the meaning of a metaphor.

When interpreting imagery, it becomes clear that ambiguity is an inherent and overarching theme: one recognises different pieces of information that the author may or may not have intended to convey. When interpreting a verbal or visual image created by a young person with ID, there is the unspoken invitation to translate the meaning of the image to the thought world of the family member or professional in the dialogue. However, that person has to be aware that this interpretation is tinted by his or her own experience; the young person with ID might have a different interpretation or purpose with the image or story. Being aware of one's own interpretive view and discussing that view with the young person with ID is needed to discover stories and explore different experiences.

Choice

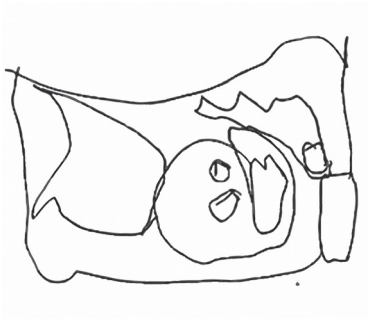
"Während die Sprache eine sequenzielle Ordnung aufweise, zeichne sich das Bild durch eine Simultanität von Formen aus [Whilst speech evokes a sequential process of arrangement, the image shows itself through a simultaneity of forms]" (Traue, 2013, p. 120). Visual images can be frozen in time. To make them come to life, there is a need to connect and to construct visual objects. An image contains multiple objects made

synchronously visible to us (Freedman & Siegesmund, 2015). Unlike visual images, metaphors, stories, and other forms of verbal imagery are told in a sequential fashion. As the story develops, the receiving partner develops a mental image of the storyline, characters, and events. The concepts involved in story interpretation are similar to those used in image interpretation: there are concepts of form, emphasis, contrast, repetition, variation, and even 'colour' (the different styles in which a story can be told). These concepts offer the other in the dialogue the choice to shift the focus during the interpretation, for example to deflect, intensify, or vivify. A clear example is found on Beau's blog. She metaphorises in one of her blogs how the expectations of others, but above all her own expectations, have affected her body and confronted her with her disability. She describes the negative effects, but uses self-mockery to convey the message that she rises above her disability. In discussing the confrontation, she chooses to highlight her achievements with her choice of words – colour' – in the metaphor: *"Body parts fly up and down without control, and my legs suddenly seem convinced they have done nothing but establishing records in running all my life. When I look at myself from a distance even I have to smile about it"* (Beau, 2012b, sentences 7-8).

Revelations

Images, quite literally, offer the opportunity to see what the other saw or wants you to see. Like visual imagery, verbal imagery provides the opportunity to glimpse how the other experiences reality. The listener or reader expects to be able to relate to the story of the other, as Underhill (2011, p. 28) described: *"We often experience metaphors as minor revelations. Intuition seems to be unveiling very real similarities in the world."* Though the verbal imagery of the young person with ID may not always be coherent or complete, stories often reveal to the listener information about the inner world and daily life experiences of the young person — revelations that may be surprising and force the other to redefine thoughts. Between the interpreter and the interpreted material there is space for reflection and interpretation; Dewulf (2012) called this the 'No-Man's Land' of imagery, which urges the interpreter to look for words or new images to be able to communicate about the interpretation. An image therefore evokes a natural reflexive process. As noted above, metaphors and verbal images are rooted in both individual and social concepts (Dolmage, 2005; Underhill, 2011). The recognition of these concepts, and at the same time the recognition of possible differences in interpretation, forces family members and professionals to reflect not only on the needs of the young person with ID, but on their own position and narrative in life as well. Imagery therefore relates to the inner self of the receiving partner. Any form of imagery evokes one's ability to connect one's own experiences to the narrative of the object at hand. Figure 20 is an example of how mind and body are intertwined in connecting to one's own experiences.

The lives and stories of young people with ID and their outlook on life harbour messages and surprises that may teach their families and professionals important lessons about their own lives. The researchers discussed how their work with young people with ID influenced their own convictions. A good example is provided by Beau (2012a) in one of her blog posts: *"Except for the fact that we undoubtedly cost money, our unwillingly received life-experience ... yields a priceless treasure of information for any support worker"* (para. 9). This quote moved the authors, since it clearly values the knowledge learned by experience; the realisation of the wealth of this knowledge changed how we, as researchers and practitioners, work together with people with disabilities.



The young woman in front of the Drawing Lab team had few verbal skills. She looked very long at her own drawing. Then she said, *"Child"*, and smiled. She caressed the child on the drawing. She looked again and said, *"Soft, small child."* Every time she looked, she revealed a bit more about what she meant by drawing this child. Whilst the researcher was not expecting a meaningful dialogue with this woman, given her lack of verbal skills, she was surprised to notice a deep connection with her through the softness she displayed towards the picture. The tone of the woman's voice underlined the softness of her movements.

Figure 20: Vignette: Connection

A visual image may protect the conversation partners from being too intrusive, since the image can be placed at the heart of the conversation. This gives the possibility of looking at the object instead of the conversation partner, but in a socially accepted manner: the so-called '180degree conversation'. Instead of having to look directly at the other (which can be experienced as intrusive), one can look at the other via the medium of the picture. Since this process is mediated by the image-object, however, it can still feel safe, even if it is unsettling. Whereas visual images may create physical distance, verbal imagery creates mental distance from the subject at hand. *"When we do not understand, we use metaphors, and they come to stand in for the literal truth, even in something as supposedly 'pure' and 'factual' as science."* (Dolmage, 2005, p. 110).

Using images or metaphors also creates a certain distance from the intimate meaning of the message. The distance that comes into existence by talking about an object instead of directly talking about one's life allows less confrontational and intrusive communication:

"The paper, or in this case the computer screen, has been my best friend for quite some time. If I am not understood, or if I do not want to tell something out loud, the figments of my imagery are penned on paper in no time. Paper is my portable therapist, and almost without costs." (Beau, 2010a, sentences 7-9)

Distance

The woman in front of the Drawing Lab team showed them her drawing. She did not look at them, but at her drawing. She smiled when she said, *"I am in love."* She talked to the team about her boyfriend: why she liked him so much, what the relationship meant to her. Having the heart drawn on paper gave her the ability to avoid eye contact and potential judgement. The researchers, however, recognised the feeling of being flooded with love, and connected with the woman through the picture.

Figure 21: Vignette: Proximity

Partners in dialogue can revisit the object, image, or story as a focus point in their conversation. Since it is inherent to a reflective process that people may wander from the core of the interpretation, or may have too many associations, both partners can use the object to return to the topic at hand. It may, however, be used as an escape as well: by exploring parts of the image, a painful or too intimate part of the story may be avoided or contained.

Distance not only creates safety, it also allows wonderment to emerge. The drawing or the metaphor becomes a 'third party' in the conversation. It is something new that has been created, which has the possibility to surprise even the author by discovering unknown feelings, preferences, or even proportions. For example, the woman in the vignette described in Figure 21 was surprised to discover, while discussing her picture with the researcher, that she had drawn the heart so big it almost pushed the people off the paper.

Paradoxically, the distance created through using imagery has a strong potential to create connection. In discussing the theme 'distance', the researchers realised that by using the safety and wonderment of distance, dialogue partners have the chance to intertwine and

become allies: allies in conjoint beliefs, but in newly discovered stories and experiences as well. By discovering the story of the young person with ID, a family member or support worker has the chance to bridge their differences in life experiences.

Discussion and Implications for Practice

Perspective

In the practice of supporting young people with ID, challenges like tacit views, insecurity, time pressure, and presumptions call for a more intense elaboration on how to use imagery as a starting point for a joint reflective process. This article describes the critical dialogue of the authors. There are many similarities in the background of the authors. Since the reflexive process was based on their respective experiences and thoughts, the perspective of the dialogue is heavily embedded in the Dutch landscape and history of care. In addition the dialogue is based on only two research projects. However, the authors find that the challenge to connect and engage with young people with ID is universal, as is the power of the use of imagery. Further research should focus on the application of imagery in research with and support for young people with ID in different settings or from different perspectives.

The use of imagery offers clear possibilities for facilitating young people with ID to express themselves, and for connecting with them. While discussing their previous research, the authors found that essential conditions must be met if the use of imagery is to measure up to intentions. By discussing some keystone considerations in this section, the authors invite readers to reflect on the application of imagery in their own efforts to connect with young people with ID, taking into account their own specific circumstances and perspectives (see also Boxall & Ralph, 2009).

Enabling Environment

In order to achieve an honest dialogue with young people with ID about their future, their dreams, and even their feelings about belonging (to a family, group, or society), the dialogue partner should be able and willing to embrace the use of enriching and deepening methods of communication such as patience, emotional support, and creativity, and of ways to make the environment more failure-free — when there is less chance for failure, there is less chance of being unable to participate. It is important for support workers to explore the concept of universal design as a framework for the establishment of an adaptive and inclusive environment for everyone, with or without disabilities. Universal design aims to have a truly inclusive society; to achieve this, one must view people with and without disabilities as equally normal. As Goodley and Runswick-Cole (2014, p. 13) wrote: *"We want to move to a time when thinking about the human will always involve*

thinking about disability." The concept of universal design is reflected in Beau's (2010c) comment:

> *"Another true wish of mine is that we will build more inclusive. Inclusive yes, not adapted. The expression 'adapted' is out of place since in the use of 'adapted' it is implied that certain groups still move outside society — not in it. If we adapt the entrance so you can enter the building.nice, but we should say: "If we build inclusive anyone can come inside the building"."*
>
> *(para. 10)*

Once these conditions are accepted as regular requirements for providing care through connectedness, one could speak of an 'enabling environment'.

Pratical Considerations

> *"The child shall have the right to freedom of expression: this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice."*
>
> (United Nations Children's Fund, 1990, article 13)

An enabling environment not only requires the right conditions and attitude for both dialogue partners, it also requires the right materials to express their image or story. Qualitatively good and diverse materials are essential to the process of making an average exchange of ideas into a true dialogue. Having sufficient time is important as well. Even though Lewis et al., (2016) explain that lack of time is not the core factor in communication barriers, having sufficient time surely is a prerequisite if a true dialogue is to develop.

Presuming Competence

> *"If you are interested in seeing another's competence, it helps to look for it."*
>
> (Biklen & Kliewer, 2006, p. 184)

Despite their apparent deficits in cognitive skills, young people with ID are more than capable of expressing themselves in diverse and colourful ways, provided they are given the opportunity. In order to allow young people to make use of these ways of expression, however, the partner in the dialogue must first presume competence in the youngster with ID. *"Intimate contact with the person and openness to the person allows you to dispense with the fault-finding, deficit-seeking framework of the professional diagnostician and to learn about the person through engagement"* (Goode, 1992, in Biklen & Kliewer, 2006). For families, friends, and support workers to really connect and communicate with young

people with ID on existential themes, it is essential that their preferred way of communication be followed. Communication partners must presume that young people with ID are competent to paint a picture about what they want in life.

Belonging

Recently, views of reciprocity and connectedness have often been incorporated in models that target the quality of support; for example, 'positive health' (Huber et al., 2016), 'humane care' (Van Heijst, 2005; Embregts & Hendriks, 2011), and 'presence theory' (Baart, 2004). The authors, too, encountered these concepts in their respective research processes and experiences.

Using imagery shows great promise to foster belonging through meaningful dialogue with the young person, as it can shape the emotional and conjunctive power of that dialogue. However, it is important to notice that belonging is reciprocal in nature. In society, young people with ID are often perceived as the partner that 'takes': for them to experience belonging, it is important that family members and support workers are open to 'receive' from young people as well. For example, the Drawing Lab research revealed that young people with ID did not make drawings about the support they received. Instead, they drew about what they can give, what they mean to people, or about their frustration that they cannot engage (yet) in certain relationships or in meaningful work.

Ownership

There is a clear need for the person with ID to feel peacefully in control of the dialogue. Life experiences have taught them that compared to others, they are often less able to exert power. The other — the support worker, the teacher, the parent — is the one who knows better, while the young person with ID is the person who receives instruction. Choosing to follow the story and interpretation of a person with ID asks caregivers, who often have learned to interpret stories in the light of their own acquired knowledge, to be brave. In order for somebody to be thought of as a fully competent participant in a relationship, they have to be seen as contributing something to the partnership (Bogdan & Taylor, 1989). The mere choice of the image or story to reflect on is an act of exchange: what is the person with ID trying to communicate to the other by choosing that object? What does the image — the made-up lullaby one's mother sang, the photographs of the house one grew up in, the artwork one made at the activity centre — truly mirror about how the person feels about himself or herself? Being able to decide the medium for communication puts the young person with ID in charge of the conversation. The person with disability, the client, is now 'owner' of the depiction at hand. So in talking to young people with ID, the dialogue partner should be prepared to step down from the position of leader to a position of co-pilot in the process of reflection.

Rocky Road

In a dialogue on existential themes, there is a need for listening, for true interest, and for having the will to get to know the inner world of the other. Whereas family members are confronted with the birth of a child with ID, and the consequent appeal for care, professional support workers tend to choose to work in the care system. Research about the motivations of support workers indicates that the tacit views they hold influence the way they approach their clients or patients (Lewis et al., 2016; Dowse, 2012). In the practice of their work, they may be confronted with these views when young people with ID behave differently than expected. Van Den Brande (2012) states that inclusion is a fundamental right that evolves around 'belonging' and 'connectedness': inclusion is by definition a relational concept. An honest dialogue may be upsetting or unsettling for the youngster with ID — yet the right to have an upsetting or unsettling dialogue is part of inclusion. Moreover, in an honest dialogue the other partner may be touched as well, or even unsettled or upset; looking for inclusion is not a straightforward process. It may at times be a rocky road, but it is one worth travelling.

Tacit Knowledge

"There is no medium of expression that is equally suited for all learners or for all kinds of communication."

(Florian, 2014, p. 482)

Young people with ID are experts by experience at living with ID in a complex society. Their support workers lack this experience. Further research should focus on how the young people's tacit knowledge can be made visible, and how this knowledge can be applied in society to enhance the QOL of others. Research on how young people with ID can be encouraged to take a formal or informal role as teacher and guide for support workers is therefore recommended.

Conclusion

By comparing their respective independent research and experiences as separate cases, the authors found that using imagery is a powerful method to engage people with disabilities in research, as well as a meaningful way for family members and support workers to engage with young people with ID. A critical dialogue was used to compare cases, thoughts, experiences, and critical incidents; this led to the identification of five themes that emerged from the dialogue. The theme of the leitmotiv shows that imagery offers the possibility of finding respite from anxiety in a dialogue, knowing that a core set of beliefs, subjects, and ideas will resurface once the drawing or the story is revisited. That images can be interpreted in different ways is shown in the theme of ambiguity, where the authors

found that discussing these different interpretations establishes a swift connection between dialogue partners. Imagery also offers the option of choice: the author, as well as the interpreter, may choose to highlight certain important parts of the image, or to hide painful or undesired parts. The fourth theme concerns imagery's power of revelation, be it small or grand. The use of imagery offers the possibility of revealing new information, talents, or questions that the dialogue partners had not previously discussed. Distance is the final theme discussed in the article. The use of imagery offers safety: first, through creating a dialogic space where a 180-degree conversation is permissible, and second, in offering a safe object to talk about, a concrete focal point. Imagery not only creates safety in offering distance, however; it also is a suitable way of decreasing distance between two dialogue partners, in that shared experiences or ideas evoke recognition.

Young people with ID, though sometimes limited in verbal skills, have no less of an inner world than do young people without disabilities. They possess reflective power on their position in life and society, and their needs, experiences, and wishes. Indeed, their very age calls for an open dialogue on life, since it is one of the developmental tasks of young people to wonder and ponder on their future. In the Netherlands, the changing landscape of care and support strategies places more emphasis on the need to connect with the inner world of young people with ID. The fast pace of Dutch society, however, and excessive reliance on instrumental communication in offering support, pose a threat to the realisation of this connection.

Imagery connects dialogue partners and creates space for safe exchange and exploration on existential themes. Based on the findings from the critical dialogue discussed in this article, there is a strong argument for applying more diverse forms of imagery in research and practice, in order to bridge the distance between caregivers and persons with ID when talking about existential questions regarding life, purpose, and meaning, as well as more practical questions that require reflection.

It is also important to emphasise that using all possible ways to communicate is not a 'special treatment' to be reserved for young people with ID. In a way, one could see dialogue with young people with ID as an example of good communication in the broadest sense: moving away from the idea of the exclusivity of spoken and written language and towards the idea of using any and all forms of representation to build connection with other people.

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3.4. Introducing the roundtable and other activities on IASSIDD Europe Athens

Convinced of the power and richness creative methods can add to (inclusive) research, I organised a set of activities at the 5th IASSIDD Europe Congress 'Diversity & Belonging: Celebrating Difference' in July 2018.

1. Workshop on the Drawing Lab based on the visual research method of graphical elicitation.
2. Workshop on photo elicitation. I presented the graphs made by others and asked the international conference participants to cut out what they recognised from their own life experience, to cut out what they could relate to.
3. Workshop with the Turkish researcher and artist Dr. Selçuk Güriçik with the help of many university students from Athens. The selected drawing details were glued to traditional Greek clothing: chitons (kimonos). The chitons were worn and shown at the final ceremony of the conference on the catwalk, whilst the models were dancing on traditional music. The QR code presented in Figure 22 leads to film and photos on this event[7]. The central theme of our catwalk was: an ode to diversity and to creative research methods; how they remind us of the always changing lives and stories of people. The stories of the people were literally moving with and moved by the people who were wearing them.

Figure 22: Catwalk in Athens

4. Roundtable organised with Alice Schippers, Geert Van Hove, Hanna Peels and Esther Joosa. To get an impression of this roundtable, we include a Vignette based on extracts from my research diaries:

[7]https://www.kennispleingehandicaptensector.nl/nieuws/vlog-congres-athene-netwerk-samen-werken-samen-leren

The roundtable – an impression

We were already in the room, waiting for the others to join. The participants – 20 people in total including us (the authors of the Post Roundtable Article) – were seated in a large circle.

We started the roundtable with an introduction. How can we define 'creative research'? We then chose not to start with definitions but with examples of discovering, expressing and presenting knowledge in research through poetry, theatre, music, painting…

After the introduction we explained the two images hanging above the inspiration wall. The story went like this… *"Imagine yourself riding your bike through the landscape of your home country. You feel the wind, you feel your pedals, your brakes are within reach. Think know about your job, working with creative research methods, exploring with music, dance, theatre, imagery, … Think about the flow in your work and what hinders you. If you want, you can stay with the metaphor, but you are not obliged. Everything that crosses your mind, put it in words or images on the wall, at the furthering 'pedal' section or at the hindering 'brakes' section or somewhere in between."*

There was no silence, no hesitation, no questions. People immediately stood up, started talking to each other and covered the wall with words and images.

After a while people went back to their chair and sat down. Together we looked at our results and concluded there was clear sense of agreement on how to further creative methods (pedal section). People commented about the importance of teamwork in using creative methods. People referred to our metaphor talking about riding the bike in a group, riding in tandem, giving reciprocal support, sharing stories, pushing somebody on a hill and about enjoying the joint ride. People also spoke about the importance of diversity in what ways you use to give people voice in research. All senses are involved on a biking tour and in research we should make use of all those senses in order to grasp, understand and analyse knowledge.

The 'brakes section', though the remarks in it were recognised by the participants, lead to more discussion: are topics like prejudice or the difficulty to receive funding for creative research truly disadvantages or can we use and overcome these 'brakes' to further creative methods? Consensus was however found on the fact that creative methods are less easily accepted, and therefore less easily published. Participants talked on the importance of transparency: what helps is a clear description of the design and layout. It became clear that all the people in the room felt they couldn't just do their job. They needed to defend themselves a lot of the time. They had to convince others a lot and that struggle was sometimes so time- and energy consuming… It felt good to talk on this, on the top floor of a conference centre: to feel that you are not the only one in this struggle, to get ideas and energy from others.

Figure 23: Vignette based on extracts from personal research diaries

With the above-mentioned activities and roundtable, we wanted to catalyse a process of reflection on creative methods. From this reflection, the participants of the roundtable and the authors identified four themes, embedded in the result section of the roundtable article.

1. Embodiment
   The power of creative research methods lays in allowing to communicate – through embodied, tangible or visible forms of expressions – about themes that are not easy to verbalise (see also Painting Pictures article).
2. Uncomfortable with messiness
   In creative research, the process of scrutinising one's own values, emotions, motivations and actions is entangled. This is personally revealing and at times leads to uncomfortable insights. This uneasiness of how to handle, treat or interpret the data causes frictions with the academic conventions, with passing in ethics committees, finding funding for your creative research work and finding ways to get your research published.
3. Connection
   As in the Painting Pictures Article we bring forward that creative research methods can evoke a closer connection between the researcher and participants, easier than conventional methods. This connection is crucial for communication of any form, but this brings also risks and uncertainty: you don't know what this connection will bring.
4. Plurality of voices
   Creative research methods enlarge the suitcase of the researchers and create more room for people to enter 'the research kitchen'. But in order to allow the plurality of voices a safe space is needed and a high level of reflexivity.

3.5. Reflections on the results of a roundtable on creative methods in disabilities research

Abstract

In these research notes, we present the results of a roundtable and a subsequent process of reflection on the challenges facing researchers in disability studies using creative methods. The roundtable took place at a conference on disability, 'Diversity & Belonging: Celebrating Difference' in Athens in 2018. The aim of the roundtable was to explore with other researchers in disability studies the challenges and joys of academic research using creative research methods. Even though the commitment to inclusive research is common in disability studies, the use of creative research methods still feels like pioneering and unconventional. The purpose of the roundtable was to discuss how we can extend the use

of creative research methods so that more people can join in research work. In these research notes, we discuss some reflections on the material that came out of our roundtable and from the reflective session we held after the roundtable. From studying these conversations, we identified four insights on the use of creative methods in disability studies: embodiment, discomfort, connection and plurality of voices.

Introduction

Disability Studies

Disability Studies is a field of study with a social justice agenda which aims to improve the lives and opportunities of people with disabilities. It therefore tends to be action-orientated and collaborative in nature. Inclusive research works towards positive change for and with people who are disabled and those who are not. Disability studies is transdisciplinary in nature so experiential knowledge, co-creation and the involvement of members of the public are essential features of the research process (Groot & Kloosterman, 2009). This involves using existing and innovative inclusive approaches to systematic data collection and dissemination (Brown & Brown, 2003; Hoppe, Schippers & Kool, 2011; Kool & Sergeant, 2020). In a recently developed consensus statement on how to conduct inclusive health research by Frankena and her colleagues (for example, Frankena, 2019), there is an emphasis on the need for the voice of the person with disabilities to be an integral part of the research process.

It may be worth mentioning that in the Netherlands we use the term 'people with disabilities' as opposed to 'disabled people'. Both are contested terms across the communities of people with disabilities but as we used this phrase at the roundtable, we will continue to use it here.

A research culture of collaborating and innovation

When creating safe spaces for the contribution of people with disabilities in research it is important to create a degree of choice for research participants to contribute in their preferred way. Using creative methods opens up a broad set of choices and a wide field of methods which offer new ways of understanding and accommodating people who may come from different life experience or disciplinary backgrounds (Kara, 2015). Jones & Leavy define creative and arts-based methods as, *"any social research or human inquiry that adapts the tenets of the creative arts as part of the methodology"* (2004, in van der Vaart et al., 2018, p. 3). Art genres that might be used are, for example, visual art, performing art, literary art or a combination (Coemans & Hannes, 2017). Until recently, co-researching with people who professionals considered 'vulnerable' or having less social power, was often done by working with their narratives, interviewing them, and working with their carers who would attempt to represent their experiences.

Research Notes

In these research notes, we share the learning from a roundtable discussion with other disability studies researchers to find what helps or hinders their use of creative methods in research. Following analysis of the roundtable material/data, we provide evidence of our thought processes which might serve as a precursor towards the advancement of new ideas and discussions in research and practice (Sergeant & Peels, 2018).

Method – Reflecting on creative methods in research before, in and after a roundtable

During the 5th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Europe Congress, 'Diversity & Belonging: Celebrating Difference' in Athens in 2018 we organised a roundtable to reflect on the matter of creative methods in research. Twenty congress attendants joined the roundtable. Congress attendees were invited to join the roundtable based on their interest or experience in arts-based research; we did not select or ask if people were disabled or not. We could hear from their introductions that participants of the roundtable were diverse in background, professional experience and nationality, coming from Canada, Greece, Spain, Belgium, the Netherlands, Singapore and Turkey. Most were working as researchers, some also as music/drama/art therapists and artists. All participants signed an informed consent form that allowed us to use the material the participants shared at the roundtable.

The Wall of Inspiration

To inspire and guide the conversation we used a wall of inspiration. This wall allowed us to share elements that progress or hinder the acceptance and use of creative methods in research. The wall of inspiration was designed in a way to accommodate the exchange of ideas. It was accessible for all participants. We asked the participants to write or draw keywords, past experiences, ideas, hopes and disappointments on the inspiration wall. During this process, the participants were invited to discuss, ask questions and share experiences so the wall prompted a community of conversation.

Bicycle as cultural metaphor

We decided to use a simple metaphor of well-known parts of a bicycle, so common in many European countries, since most participants would understand this metaphor and how the different parts of it work.

The pedals (left) represent ways to further creative methods.

Figure 24a: Pedals © René Krewinkel

Figure 24b: Brake © René Krewinkel

The brakes (right) represented factors that either hinder or balance the use and acceptance of creative methods. The images were pinned to the wall with a blank space between these sides for ideas that don't fit either of these sides.

The roundtable led to a range of brakes and pedals showing them within a (broader) continuum of methods and paradigms in science and practice (Peels & Sergeant, 2018).

We used the material from the roundtable as a starting point for an inductive thematic analysis with further reflection on the use of creative research methods. This step of reflection was done by us authors a few months after the roundtable through discussion in live meetings and through writing and re-writing together. The reflection brought us in a space somewhat reminiscent of Bakhtin's ideas on dialogic interactions and relationships thus making room for multiple voices and ways of seeing that are unique and different from each other (Robinson, 2012). Differences and contradictions were welcomed as the diversity of the voices added complexity to meaning making together (White, 2015).

Results

From this process of organising the roundtable with over 20 participants, the reflection sessions with authors and the writing and re-writing together, we identified the following insights in the use of creative methods:

1 Embodiment

"Precisely because we are never merely objects, but simultaneously living subjects – sensing, moving and experiencing – our materiality makes us open and vulnerable to the world."
(Wehrle, 2020, p. 500)

Discussing this theme of communication brought us to the concept of 'embodiment' and how people express their ideas, feelings and stories through their bodies, in various forms, in tangible or visible forms of expression, for example through a self-made photograph, dancing or drawing. Such material constitutes communication and can therefore be considered valuable data.

By using the lived and physical aspects of the body (Wehrle, 2020) to gather data about a story or concept, we allow the richness of data, both cognitive and physical concepts, to enter and extend 'the picture' (Kara, 2015). Data are not then seen as isolated items but as intertwining parts of a story. As Hannes has said, *"If I had not been there, I would not have told my story like that."* (2019). Embodied knowledge provokes strong responses from both the researcher and the researched and therefore needs outlets, opportunities for sharing. Such emotions can provide *"a catalyst for learning beyond traditional, cognitive ways of knowing"*, as observed by Lawrence (2008, in van der Vaart et al., 2018) and lead to stories not yet told or heard (Jensen & Penman, 2018). A more complete, richer story then is the subject and contribution of the research.

Creative methods stimulate not only the dialogue between researcher and research participants but the whole data gathering process becomes as a multisensory experience. One can appreciate contextual elements like the space where the data gathering takes place, the choices of people to include or exclude elements of their own story and the responsibility of the participants to be part of the reflections and analyses made. One of the participants of the roundtable wrote it allows 'new ways to see'. Other participants wrote that 'including emotions' or 'intuition' was important in promoting creative methods in academic research.

2. Uncomfortable with messiness

Data gathered by creative methods are far from 'separate things'. They are relational, connected with emotions, narratives and the varied, complex circumstances of both the researcher and the researched. The concept of 'necessary distance' between the researcher and data is challenged. Without the relational context of communicator and listener there is no intimate exchange and therefore new learning. This may cause uneasiness and dilemmas for people used to traditional methodological assumptions of researchers being separate from the process. But in inclusive arts-based research, researchers and their research practices are rightly changed by the feedback from the research participants. Analysing their stories may touch the researchers and highlight painful aspects of their own lives.

On the inspiration wall someone wrote, 'evel of confidence!' (on the brakes side); 'action- and change-oriented orientation' (on the pedal-side). In the analytic processes, we discussed how we too recognised the need for more confidence at times to become action-and-change oriented when promoting arts-based research with community members.

Poetry can also work in powerful and meaningful ways but can also confront the researcher, provoke emotions and, methodologically, create uncertain about how to treat and whether to attempt to interpret the data or let it speak for itself. This is a highly political matter given the history of professionals speaking on behalf of population groups often resulting in misinterpretation of experience and need.

Participants in the roundtable noted the struggle they experienced in their work in terms of getting projects funded and the research results published given how many journals still subscribe to very specific academic conventions (van der Vaart et al., 2018). People also raised issues of research ethics committees whose members were not familiar with arts-based research or were concerned about participant confidentiality. The words of Tina Cook (2009, p.11) summarise the uneasiness with messiness, *"The messy area is a tough place to be"*. But we also agree there is no other way if we want to ensure more disabled research participants voices are heard to promote better understanding of experience. Grappling with journals and ethics committees is part of the struggle necessary to ensure broader dissemination of research work.

3. Connection

This theme was highlighted in several of the posts on the 'pedals' side of the inspiration wall: 'empathy and love' or 'producing not to score brownie points'. Creative methods evoke closer connections between researchers and research participants and more quickly than conventional methods. Moreover, trends in public sector research expect not only accessibility in research methods but inclusivity in which there is an expectation that researchers and research participants will collaboratively analyse the data. The research relationship is a connection that requires mutual trust, respect, interest and an investment in the cooperation. It involves all parties being invested in time, patience and openness of mind to engage in the art form like dance, theatre or other genres. This investment, however, carries with it uncertainty: as a researcher or as a research participant, you don't know what the participation will bring you. Professionals have to suspend their expertise and foreground that of their research participants (Anderson, 1992).

4. Plurality of voices

Diverse methods of gathering data expand the possibility of finding different knowledge. Creative methods offer a similar potential to inclusive research as they invite different voices and point of views to build a better and more overarching understanding of people's lives. Openness and clarity about each other's roles, about relationships and the timeframe are important (Nind, 2014). Time is needed to get to know each other well, to be able to be mutually vulnerable. One of the participants of the roundtable sketched glasses with the writing: *"care, politics, research, arts/design"*. It is like wearing glasses with different purposes and means in sight. The plurality of voices requires creative approaches to research but also the need for safe spaces to conduct research. While many research participants are vocal and articulate in identifying their views, others struggle to find a voice or a means of expressing themselves so researchers have a responsibility to research and co-develop what creative methods are suitable for hearing people with disabilities.

Concluding thoughts

A growing preoccupation in the field of Disability Studies is how to gain a clear understanding of people's wishes, hopes and anxieties (Brown & Brown, 2009; Schippers, 2010; Brown & Faragher, 2014). Exploration of people's wishes, their thoughts and needs as expressed by them is always important and sometimes a challenge if individuals have sensory disabilities which impact on responding to and expressing language. These are challenges researchers need to address with their research participants to ensure the needs of people with differing disabilities are heard.

The field of literary and arts-based research is a wide and established part of the qualitative research field. Although the credibility and acceptance of creative methods in mainstream research is now widely accepted, the results of our process however lead to the conclusion that it still proves a challenge to researchers. While most of the notes on the inspiration wall in the roundtable highlighted the positive aspects of creative methods, many researchers identified difficulties in progressing creative methods of research with people with disabilities.

These research notes summarise reflections from researchers in disability studies who had experience of or were considering the use of creative research methods which promote inclusivity with people with disabilities. We have found it helpful to document creative methods using fieldnotes or an audit trail to analyse what happens during the research process. Awareness of the process and inclusion of all researchers and participants require preparation, training and support before, during and after the process. But at the same

time, protocols don't precede but grow out of the moment of engagement through collaboration, transparency in research relationships (Kuntz, 2010).

These research notes, it made us think back with pleasure to the process of working together with so many people from different backgrounds. We'd like to extend therefore our gratitude to all those involved.

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Chapter 4 – Collaboration

"I am not just a disabled person, not just an expert by experience, not just a co-researcher, I am more than that. I also want to be seen as a woman, a researcher, a traveller ... There is still a long way to go in this. I always say: "just act normal to me, don't make me special"."
(Sandvoort, 2019, September)

This chapter is based on:

Sergeant, S., Peels, H., Sandvoort, H., Beau, Schelfhout, P. & De Schauwer, E. (2020). A Collective Biography on Collaborative Research. Manuscript submitted for publication.

4.1. Introduction

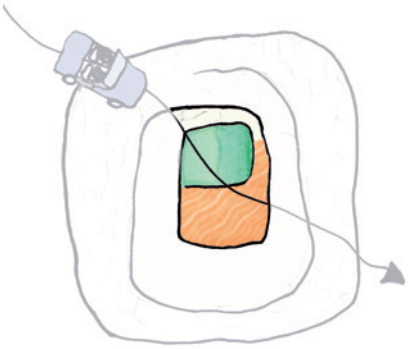

Figure 25: The Second Layer of the Sushi © Sanneke Duijf

As depicted in Figure 25, we highlight on the second layer in this fourth chapter: the encounter with two other duos engaged in inclusive research.

Although there is an extensive body of inclusive research projects with people with disabilities, until recently few published papers have offered reflections of the process of doing such research or provided descriptions of the roles the researcher with experiential knowledge in the research process (Bigby & Frawley, 2010). Williams, Simons, and Swindon People First Research (2005) were amongst those researchers who reflected on inclusive research processes. They found the researchers juggling two processes: at one hand ensuring that the researchers with experiential knowledge were in control and at the other hand ensuring that the research progressed. Other challenges may be systemic – as Nind and Vinha (2014) also mentioned – such as a lack of understanding of the underlying tenets of inclusive research by funding sources and ethics committees, and ensuring research is inclusive while complying with standards of academic rigor (Strnadová et al., 2016).

The following article is on the collaboration between researchers with academic background and researchers with experiential knowledge. Through the Collective Biography Method we – Henriëtte Sandvoort and I, Hanna Peels and Beau, Elisabeth De Schauwer and Patrick Schelfhout – examine the experiences and difficulties in the collaboration in research, in co-creating, in all the phases and through all the complexities of the research process.

4.2 Collective biography on collaboration

Abstract

In this article the work between researchers in inclusive research teams is analysed, drawing on Fine's (1994) concept of 'working the hyphens': the conscious exploration of what happens in those moments roles or contexts overlap. The authors contribute to the understanding of how collaboration in inclusive research teams works, and how to realise transformation in ways of working together. By using a collective autobiography where we worked with our first memories, we explored the close collaboration that researchers with and without a label of disability experienced. 'Working the hyphen' meant: togetherness which is crucial for the construal of 'us'. We all experienced the necessity of a permanent meta-conversation on accessibility, growth and thresholds in our working relationships. We encountered several dilemmas in sharing responsibility between researchers. By consistently being alert to and transparent about the move-ability in the hyphen-space, the relational work between researchers can be deepened and made productive.

Points of interest

The six authors are part of three inclusive research pairs, each with one researcher who has an academic background and one researcher who has personal experience of living with a disability. We look at the working relationships in inclusive research. We want to understand how we as researchers work together, and how working together changes the research work and the researchers themselves.

We use a method called 'collective biography': this method is based on memorywork, telling and sharing lived experiences. We talk about our working together and how we experienced doing inclusive research. We learn three important things:

1. We need to spend time together as people as well as working together before we each see the team as 'us';
2. We all need to talk about our relationships within our teams, and we need to plan and make time for this;
3. There are challenges in sharing responsibility between researchers in inclusive teams.

Introduction

When working together in inclusive teams, the authors experience a common struggle: how to describe their working relationships in the context of inclusive research. We find the broadly used terms 'inclusive research' and 'co-research' abrasive and unilateral now that we have conducted research together for a long period of time. It feels like these terms fall short of describing the delicate balance between the personal, experiential and academic knowledge of the researchers involved. We fear the risk of creating or perpetuating a hierarchical relationship between researchers, involving how knowledge and research are valued, comparison between previous learning opportunities and experiences, living and working conditions... The agility between researchers is not cogently contained in either the term 'co-research' or in 'inclusive research.'

For this reason, we decided to engage in a Collective Biography (CB) process (Gannon & Davies, 2006; De Schauwer et al., 2016) with several researchers who have already worked together several times in inclusive research, giving us the possibility to explore and unravel our ways of working. Davies and Gannon (2013) describe CB as a way to methodologically compare and connect abstract data like memories, experiences and thoughts. We go back to our first memories when we think of working relationships in inclusive research. We write them down, read them aloud to each other, think about them together in several conversations and rewrite our stories once more. This is a lively and patient process that fits well with our research questions: What does it mean to work together in inclusive research. How do we see our own and each other's position and involvement? What practices improve our experience of researching together? We worked with the analysis of the stories each researcher wrote and the conversations of the group.

The author team for this article exists of three pairs of researchers who have collaborated in research for a long period prior to the CB workshops. Pair 1 is Henriëtte Sandvoort and Sofie Sergeant. They work together to develop and organise training, coaching and intervision within their research project 'Working Together, Learning Together' to support and catalyse the cooperation of disabled and non-disabled researchers in other research projects. Pair 2 consists of Hanna Peels and 'Beau' (pseudonym). Hanna and Beau research experiences of daily living in facilities that provide care for people with (intellectual) disabilities. They do so by analysing the blogs Beau has written for years. Pair 3 is Patrick Schelfhout and Elisabeth De Schauwer. They work together in Our New Future, a Flemish self-advocacy movement. Patrick and Elisabeth have several shared research experiences around support and collaboration. The link between inclusive research and consequences for their personal lives are repeatedly discussed in this self-advocacy movement.

Context: collaboration in inclusive research

Inclusive research emerged in England and Australia in the late twentieth century, alongside deinstitutionalisation, the emergence of self-advocacy and a discourse of human rights. The motto of the self-advocacy movement, 'nothing about us without us' (Charlton, 2000), has been reflected not only in the areas of social inclusion and self-advocacy, but also in the field of disability research. As people with disabilities have gradually been incorporated into research work, there was at first mostly a desire to include their voices, perspectives and views. In the last decade, however, there has been a proliferation of studies in which disabled people have played an active role – for example by setting research agendas, being part of selection committees, and serving as experts by experience paired with conventionally trained researchers – in research on issues affecting them (Nind, 2014).

The term inclusive research is defined by Nind (2016: p. 24) as research that is *"conducted with, by and sometimes for ... but not on people with disability."* Varied methodological approaches are employed, which may generally be characterised as placing the lived experiences of the participants at the centre of research activities, and providing for more democratic approaches. These include participatory research, where disabled people work in partnership with academic researchers, and emancipatory research, where the aspiration is for disabled people to lead and control the research, changing the relationships governing research production (Oliver, 1992). Thus, inclusive research is about both empowerment and richer research: *"Inclusive research can add to our knowledge of others and ourselves. It can provide a means for people to take power in their own lives. It can also be used to promote and support change through advocacy"* (Johnson et al., 2014: p. 83). Inclusive research can improve the quality of research, as partnerships help to ensure that research designs are less harmful to participants and their communities, more accessible, and promote feelings of respect and trust, which may subsequently engender greater participation in research. Inclusive research requires *"an ethic of respect for the lives, views and experiences of people with intellectual disabilities, and for the knowledge they hold and can add to the research process"* (Chalachanová et al., 2020: p. 148). But who decides on the conditions under which 'they' can join 'us' in the research work? Rancière (in: Biesta, 2019) points out that inclusion should not be understood as adding more people to the existing order, but as a process that necessarily involves the transformation of that order.

Though literature on relationships in inclusive research teams is emerging, there is little written about the impact inclusive research has on the researchers themselves, with Wagle and Cantaffa's (2008) exploration of identity relations in qualitative research one exception.

Chalachanová and her colleagues (2020) published their research on how academics and people with intellectual disabilities initiated and sustained research relations. They introduced the concept of 'alongsiders' – developed by Katherine Carrol – (Chalochanová et al., 2020: p. 149) in inclusive research: conceptualising all researchers involved as agents of change, engaged in an honest and reflexive working relation. It is necessary to address the risk within the inclusive research team that the researcher have different experiences of belonging. Research is a highly distinctive world: *"… in many cases the co-researchers feel excluded from complex discussions due to their learning difficulties and are acutely aware of the hierarchical nature of the academic context"* (Riches, O'Brien and The CDS Inclusive Research Network, 2020: p. 3). There is also a risk of commodification. Walmsley (2004) suggests that participatory researchers in the field of disability are driven by the desire to erase difference.

It is certainly clear that a high level of time and effort is needed to listen to the ideas and emerging narratives of our disabled colleagues (Chapman, 2014). Literature from self-advocates who have an intellectual disability (Harrison et al., 2001; Martin, 2006; Cromer, 2002) reflects a collective emphasis on being respected as people with equal rights, feeling like equal partners, and being included in all aspects of research community life. They have stressed that learning and making friends were just as important to them as finding the answers to questions (Strnadová et al., 2014). Woelders et al., (2015) argue that expectations arising from an idealised vision of inclusive research can interfere with building good relationships and research practices.

Research into the dynamics within inclusive research teams often focus on how power dynamics are managed within a particular project or partnership. For example, Bigby, Frawley and Ramcharan (2014: p. 56) describe in some detail how *"trusting relationships and dispersed power"* are a core component of their collaborative group model for doing inclusive research. They relay how members of one group got to know each other, building trust and camaraderie through regular contact that included banter, mutual respect, doing what they promised, and being collegial in their decision-making. Such relationship-building, they argue, takes skill, care and time. However, Frankena et al., (2019: p. 720) observe that the structured study of roles and relationships in inclusive research has *"received little attention"* and *"focused mainly on short-term projects."* Partnerships can begin by being open to people who need to *"learn on the job... reflecting, and adjusting to experiences along the way"* (Woelders et al., 2015: p. 532). Through critical reflection, partners may recognise and assess socially constructed barriers placed on them and pursue control over their lives (Stack & McDonald, 2018).

'Working the hyphen'

The authors of this article all are engaged in inclusive research projects. We recognise the transformation and personal change that occurs whilst researching together. To be able to further explore this transformation, we draw on the concept of 'working the hyphen' developed by Michelle Fine (1994). Hyphens link two words to indicate a combined meaning, or divide a word at the end of the line. Fine, a feminist psychologist, conceptualised the notion of 'working the hyphen' in researching issues of objectivity, representation and identity in people who belong to two cultures, two religions, etc. Fine emphasises how identities or responses were not only influenced by the two groups people belonged to, but that their identity is often shaped where two identities overlap – the so-called 'hyphen-space.' Moreover, Fine encourages researchers to reflect on moments were the 'Self' and the 'Other' are joined; she describes the moments when this happens as the 'hyphen': *"exploring how we are in our relationship to 'the Other,' the context of our subject, understanding that we are all multiple in these relationships. I mean to invite researchers to see how these 'relations between' get us 'better' data, limit what we feel free to say, expand our minds and constrict our mouths, engage us in intimacy and seduce us into complicity, make us quick to interpret and hesitant to write"* (Fine, 1994: p.72). Fine notes that relationships between researchers and respondents are multiple in nature, and agentic in the sense that researchers and respondents shape each other's identities and actions. Humphrey (2007) gives an example of that transformation when she, building on Fine's concept, describes her struggle with stepping in and out of focus groups in her research. She notes how she came to see her involvement in inclusive research as *"activat[ing] the hyphen by journeying between different life-worlds":* she changed through the research process, and this altered how she approached new research processes.

Fine's concept of working the hyphen is used in qualitative research in several fields, including ethnographic research. In our respective research projects, we find similar dilemmas on how to position ourselves in regard to the researchers we cooperate with. We perceive the need to reflect on how to prevent linearity or hierarchy, how to be aware of differences in perspective and experiences towards the research theme, and how to be able to not only note these differences but to analyse them and acknowledge the influence they have on our research processes and outcomes. Cunliffe and Karunanayake (2013) also define, building on Fine's work, four hyphen-spaces in ethnographic research involving minorities: insiderness-outsiderness, sameness-difference, engagement-distance and political activism-active neutrality. We find these hyphen-spaces in our research processes as well, as will be shown in the discussion of our CB workshops. Using Fine's concept of 'working the hyphen' offers us a perspective on what happens between the 'co' and the 'research,' the agility between different concepts of knowledge and cooperation, the area that we will henceforth call 'the hyphen space of inclusive research.'

Method: Collective Biography

Writing a Collective Biography (CB) is a method of research that consists of telling and sharing lived experiences on one or more specific concepts. Bronwyn Davies and Susanne Gannon (2006, 2013), inspired by the collective memory work of Frigga Haug (1987), used CB as a feminist research methodology. CB drew on participants' stories of their early memories to analyse processes, thereby putting theory to work: everyday experiences meet theoretical insights. Rather than being interested in truths of particular individual subjects, the topic of a CB is to examine the ways in which subjects, with different abilities and lived experiences, are discursively, affectively and materially constituted in particular moments of close collaborative research. What makes the researchers feel valued as researchers and at ease to contribute?

For our CB, the point of departure was the article: 'Echt samen | Really together' (Van Asselt-Goverts et al., 2017). We all read this article beforehand and used our reflections on it as a starting point for the CB. We had sessions where each researcher worked alone, sessions in familiar pairs, and sessions where we all worked together. Before the first workshop, each author individually wrote a personal story on key thoughts, experiences and memory regarding the process of inclusive research. All authors could write their stories down, but in a situation where this was not possible, stories could be recorded or collected using other means, and transcribed for sharing.

We continued our CB process by meeting in person for full-day workshops. During these CB workshops, we created a safe context, with patient and respectful listening (Davies, 2014). Two of the pairs (Pair 1 and Pair 2) met in August 2018 to discuss their individual stories; due to unforeseen circumstances, Pair 3 was unable to attend this meeting. We listened to and talked about each other's stories: we asked questions, thought of what was recognisable, and brought in our own experiences. After this step, the research partners discussed the stories that had emerged, talked about potential responses and rewrote the stories in each other's company. This step allowed us to make visible connections between two stories, and served as a step to further explore overlapping questions, themes and experiences. The next version of the six stories was discussed, and on the basis of this reading and discussion, we reworked our stories once more in our familiar working pairs. A final meeting in February 2019 brought all the authors together to discuss cross-connections in their stories.

We read our stories once more out loud, and we were able to ask questions and dig further to make sense of the collaborative process that is fundamental to inclusive research. The cross-connections between the stories were analysed and intensely discussed, recognising

the statement of Davies et al., (2013: p.686): *"Such research demands of the researcher new skills of listening to the minute details of life as it unfolds in all its multiplicity, in its repetitions and in its leaps into the unexpected and new."* In telling, listening and rewriting, the stories remained intensely personal, while at the same time becoming part of a broader story that surpassed our individual stories. It was in telling our stories, listening to each other, in witnessing and acknowledging each other, that it became clear what it is like to be part of inclusive research.
During the writing process, we started with three research pairs merging their experiences, and used 'working the hyphen' as a central concept to step away from the more 'common' discussions and experiences on inclusive research. This allowed us to bring out those undiscussed notions and incidents that occurred in the hyphen-space.

The Collective Biography process offered us an exceptional chance to make time and think together with other inclusive research teams who shared the experiences of working the hyphen. We felt how comparing abstract concepts in a group of 'research peers' worked as a mirror of our own inner thought processes (Busse, Ehses & Zech, 2000). Besides a sense of recognition, of the process also highlighted uniqueness: even though we arrived at a shared story, the specific interpretation of this story differed from person to person. We recognise with Nind and Vinha (2014) the importance of time to reflect, to talk things over, the cruciality of sharing purposes but also of spending enjoyable time together.

Results

1. Construal of 'we'

The story of one researcher labelled as intellectually disabled resonated with every one of us. This is his story about working together with a non-disabled colleague researcher, Lisa (pseudonym), on a research project around the use of social media with and for persons with an intellectual disability. The collaboration was perceived as negative, because it did not feel workable and none of the researchers involved was able to change this. This led to a discussion of the exchange between the researchers, and of how important the reciprocal relationship is for both. It is a matter of belonging and feeling a 'click' with each other. The research partner telling the story said:

> *"Doing research has to do with relationships between people. The first time I met Lisa, she said: "If you want to stop, just stop." What should I think about that? It made me think she did not like me. I need to feel a 'click.' But with Lisa... sometimes she was too friendly, like she was talking to children. It pinched, how she talked to me. When I heard that she talked to her colleagues in a different*

tone, I had the impression she thought she was lowering herself. I did not always feel 100% respected. That gave me a feeling of inferiority, if I may express it in that way. She thought: "'I have a higher education, I have done studies, you are just someone with a disability". Maybe that's not meant to be that way, but still... She was not clear how she felt about me, how she saw working with me. It felt like she was obliged to cooperate with me, but in fact she did not want that. That was the feeling I had."

The so-called 'click' the co-researcher describes in his story was recognisable for all the authors. It fits with several of the hyphen-spaces that Cunliffe & Karunanayake (2013) identified, especially with the hyphen-space of sameness-difference. A presumably well-intended remark by the researcher evoked the feeling of difference in the other. Collaboration starts with creating a 'we' that every researcher involved feels comfortable in, and that requires 'a click': shared ways of working, shared engagement, shared passion/ambition to look for possible answers together, and confidence that each person will contribute to the searching. It also has to do with tangibles like the tone of voice: can we use the same tone to address all colleagues? Can we start from and keep on returning to a sense of equity, and feeling at ease with each other's competencies? Can we feel in our relationship that we expect something from each other? We know that we start out with and work with different abilities, but we respect each other and value each person's contributions while working together. The maintenance of 'we' creates an important impetus for us to move into the research and to experience a shared responsibility for whatever we come up with. Another researcher shared a memory from a past research collaboration:

"I have not had much feeling of 'co' yet. I want 'co' all-over: looking together at what and how we will investigate. So far, they have only done things for us and have not explained what it is for. They have already said what needs to be done, but they do not plan and discuss with us. In research, I really expect them to do something with what I have given."

By looking at our stories together, we discovered what kind of researchers we became by working together on research together. First and foremost, we realised inclusive research is about allowing the relationships between researchers to grow by sharing together, being dependent on each other, and making every stage of the research accessible. It doesn't mean that everyone has to do the same thing all the time, or that we know in advance what it will be necessary to do or how we will handle thresholds during the research process.

"I think it's important to fall back on Lisa if I don't feel safe or if I have questions. This week I have to take photos of how I use social media. Nothing

comes into my head. She needs to set me in motion. She introduces 'PhotoVoice' as simply taking pictures. She does not explain the research methodology, she does not discuss with me what we are doing, the overall picture. I expect her to take me into research methodology and to think together on how we will use it."

As this story illustrates, truly inclusive research is about realising: we're in it together, it is our research, but we don't have to contribute in the same way and to the same extent. Contribution is about negotiating. It's about making sure that we have in mind what we want to achieve, making sure that everybody is able to follow this in his/her own manner, drawing up a plan in which everyone has a part to play and then gradually being responsive enough to make necessary accommodations as the work is carried out. All of us sometimes come up against boundaries, but interdependency within the team of researchers should work to absorb and/or overcome this.

We can use each other's multiple knowledges and skills, as long as we are open and honest about what we can expect from each other. But even when the shared 'we' feeling has been created, we acknowledge that we are all subject to moments when asymmetrical relationships relating to the high status of scientific knowledge and academic researchers is felt as a barrier to the 'we' in the research field. We all have the feeling that research involves reaching higher than we are accustomed to, perhaps even higher than we are capable of reaching. We are all striving very hard to fit in and be recognised as 'good' researchers. In this striving we recognise the hyphen-space of 'innerness-outerness' (Cunliffe & Karunanayake, 2013), as described by one of the researchers reminiscing on their experience at a conference:

"When I came home, I was troubled for a while, I felt kind of lost. Not knowing where I fit in. I recognised what researchers talked about, it is the world I live in. But to take me off that world is kind of strange. I realise I am yearning to fit in. But I know for sure that I can't do that on my own."

The possibility of working on one's own terms was found to be extremely important by all researchers. However, some felt they needed to go the extra mile to convince others of the value of their insights and work. We spoke about how an ideal research process would work with a clear structure in place, but with fluid contours so everyone involved in the research can work the way they need to. It is necessary to give each other the possibility to steer, which may lead us beyond the boundaries of what we already know. It is necessary to keep on launching possible suggestions, and to see whether others can go with the flow and continue. To start from a proposition and then to be able to let go and transform ourselves through a shared process was perceived as very productive by all researchers. As

one recalled, this was not always in the case during former research collaborations where PhotoVoice was used as a method for data-gathering:

> *"I told her: "I can describe it better than recording it in a photo. I don't know what photo to take." She insisted: "take a picture of your computer." That doesn't help me any further. I don't see the point. Does that remind you of using social media? A photo of my computer... Come on! That is too simple... My mind then jumps to zero in one go... I work much better differently: the other says something and that brings me to things, that makes me think, that wakes me up. That brings me to my experiences, what I know, what I want to add to it."*

2. Importance of an ongoing meta-conversation on collaboration

Thinking about conditions for solid collaboration brought us to the second section of our CB findings: the importance of what we call the 'meta-conversation.' We see this meta-conversation as an ongoing discussion that allows us to reflect on how our collaboration and communication are evolving during the research process. We found, however, that this can be complicated by the conditions for inclusive research, such as dependency on the other for guidance, practical help and (emotional) support. We discussed the importance of taking each other's diverse bodies of knowledge seriously. but also sharing insecurities about the research process. Disabled people are more frequently confronted with insecurities during the research process. They often assume that non-disabled researchers are always in control and know what to do and think. We need to be and stay aware of this in our relationship. It is often a matter of time, of simply waiting long enough and giving each partner opportunities to think and to develop ideas and insights. In sharing ideas and insights, we are open to influences and add-ons at each moment of the research process.

> *"For example, when I ask my research partner what the next step is, and she says "I don't know." We have to figure this out together. Because she says she doesn't know, I get the space to think for myself and come up with an idea. This makes you equal, and one is no more than the other. If one of the two parties shows vulnerability, this creates the possibility for the other to support in any way."*

In the meta-conversation, not only is research work a focus, but also the invisible work of bonding and the importance of personal encounters. Although these are important parts of the research process, a lot of this work remains invisible unless we deliberately bring it to light. While it may occur between, during or next to research activity, its impact and effect on the research cannot be underestimated. Creating and maintaining this personal connection is not about sharing all of your personal life and your biggest secrets, but it involves cementing connections with each other, which includes insights into your

personal life, views and interests. It is a natural sharing that happens between colleagues, but in an inclusive research setting, it needs and deserves more attention. Completely separating personal and professional life seems harmful in inclusive research.

> *"Lisa [pseudonym, colleague in past research project] doesn't know me yet, that's the problem. She cannot imagine how to deal with me. I am someone who does not show easily how I feel. If she remains aloof, I will not come any closer. Will [pseudonym, other colleague in a past research project] is looser about that. Will calls me easily. He calls me once in a while, ever since that project. Lisa draws lines between work and life. We don't get to see much of her. Opposite is Will, who is going to talk to me about Netflix, programmes he watches. "Do you have anything new that you are viewing?" That creates a bond on one subject, for her it's only about that research. I do not know anything about her life. Will also watches Netflix, you already have one common topic. Lisa is also on Facebook with me. Why? Because it is necessary, because the research is about that! Collaborative working is important. But I think that apart from your research work, you should also be able to talk about something else in order to collaborate better within that research."*

The importance of team-building came forward during analysis of our individual stories. There is a lengthy process of getting to know and trust each other, and this is an unstable and at times difficult process with unknown outcomes. However, taking the time to build this relationship is imperative for solid collaboration, and relationships need to be negotiated at all times. As one member of Team 3 wrote:

> *"Collaborate with people with disabilities in research ... It is always balancing... It is always searching... In doing research together, I often fall back on people I have known for a long time. There is already a history and a repertoire to fall back on, both of us. Otherwise it is a lot more scanning, trying, seeing what's coming, playing on it and giving or receiving it new opportunities."*

Another topic that must be discussed during the meta-conversation is the need for support. Academic researchers have a crucial role in supporting people with intellectual disability so that they can be involved in research (Walmsley, 2004). Despite this, researchers rarely specify their involvement or clarify their role, and often dismiss or discount the support skills and experience that they bring to the research project. In many research projects, a separate advisor or support worker is appointed to support the experts by experience. In our collaborative biography workshops, we had a lengthy discussion on this subject. Support is needed when it's needed. It is important to discuss potential needs

beforehand and check in continuously to create the best possible conditions for everyone to do research. However, the place and need of support can differ between persons, and might change over time. We also discussed how support is often exclusively targeted to the experts by experience; in our experience however, we find that the collaboration and communication between researchers in a team is often in need of support. Giving feedback and emotional support is part of being clear and regarding each other as partners in the research process. In inclusive research, however, we see giving honest feedback as particularly delicate. First, the asymmetric status of the researchers harbours the risk that one of the researchers will hesitate to speak up. Second, giving feedback to an expert by experience might involve topics related to his/her disability. The liaison between the academic world and the daily life of researchers is therefore felt by the authors to be the most sensitive area, one where support is needed.

3. Handling dilemmas in responsibility

A third issue that emerged in the CB workshops is the feeling of responsibility and unease. Through inclusive collaboration, new experiences bring insights into persistent imbalances within and outside the research work. The genesis of these insights occurs in the hyphen-space of our close engagement (Cunliffe & Karunanayake, 2013). It is very difficult for the partners in research to see where the responsibility towards each other begins and ends. Sometimes the vulnerabilities we each experience in our daily lives are situated somewhere else, or not acknowledged while we are collaborating. A member of one research pair said:

> *"A few days later I spoke to my co-researcher again. Together we looked back at the conference. She tells me she had a very difficult time after the conference. I don't understand that at first—at the convention, she seemed very much in her element. She tells me that it hurts that there is such a difference between how inclusive the conference was and how less inclusive her own home is. Especially on returning, the difference was just too big. She really had problems with it for days. (...). At the same time, I feel guilt during this conversation. Guilt because it is me who asked her to attend this conference, or to get involved in the research in the first place. Guilt because she sees or experiences things that also cause pain or make questions rise. And something against which I cannot protect her. Not that I should protect her, that is not my role; but I would really like to—especially at moments like this, when I feel guilty. I wonder if I can ask this of her."*

Co-researching is a process that does not end with the production of a research report. The personal investments made by co-researchers with intellectual disabilities brings a greater emphasis on and responsibility to ensuring the findings will have an impact on the daily life of the co-researcher, though policy or practice (O'Brien et al., 2014). Stone and Priestley (1996) already mentioned the emancipatory drive of disability research as one of

the principles of ethically good research: 'what's in it for them?'. While the experts by experience described this emancipatory drive as inspirational, the academic researchers described the weighty task as both a goal and a burden.

Moreover, we all recognise the different possibilities that daily life harbours for disabled and non-disabled people. These differences risk strengthening the asymmetry between researchers, for example in the capability to understand lectures or to attend conferences abroad. These differences also came to the surface during the CB workshops. Sometimes one researcher's memory triggered a thought, feeling or conclusion in another, but this result was not always congruent with the feeling the initial researcher had when revealing his or her memory. This led to discussions about the content, meaning and embeddedness memories: who 'owns' the explanation of experiences? For example, dining out with four of the researchers was viewed by one researcher as a thorough example of inequality, since another researcher remarked on how seldom this kind of event occurred due to lack of personal support. The researcher who was viewed as bringing forward that inequality, however, experienced the dinner as a nice outing, without feeling disadvantaged in her personal life. We identified several moments like this where academic researchers, because of this feeling of responsibility and guilt, tended to have a grimmer view of the research process than the experts by experience. Each academic researcher recognised moments where their research partner pointed out the importance and end goal of the ongoing research, thereby encouraging the academic researcher. We concluded that disabled persons have a lot of experience in dealing with 'inconvenience' and embarrassing situations. As one said:

"It is with the greatest of ease that I can speak about uneasiness."

The theme of mutual care should be given a place within the meta-conversation. We need to talk about how we take care of each other in our research projects and why. These conversations can take place informally along the way, but can also occur in a more formal context.

Conclusion

In discovering the hyphen space between the 'co' (the disability, experience, inclusive part) and the 'research' (the academic, goal-driven science part) through the Collective Biography method, we found that our concerns about the term 'co-researcher' are based in the continuously changing relationships between researchers, in the similarities and differences we encounter in the hyphen space. While research might be experienced as a more or less individual task, which for professional researchers generally happens in an often-competitive academic environment, the interdependency between researchers we found through our CB work teaches us that rich experiences occur beyond the formal borders of research tasks. Occasions need to be created in which research teams discuss

these experiences, and come to understand how they influence and even enrich the research work (Fine, 1994).

By using Fine's concept of working the hyphens, we transformed the way we conceive of and organise academic research: we can't just repeat familiar steps whilst trying to include a researcher by experience. Drawing on these crucial but invisible experiences requires making a conscious choice to reserve time to do so, and developing formal and informal steps within the research process where lessons from what happens in the hyphen spaces are acknowledged. Based on our CB, we propose making the definition of these borders, and of the 'we,' a joint task within each inclusive research process. We emphasise that these borders should not be defined as static lines, but as a topic to be revisited when needed. Working the hyphens is an intense and often deeply personal process that may at times come too close to one's own personal limits. Making the borders of research cooperation more fluid allows researchers to withdraw from a hyphen-space when they need or want to. A meta-conversation helps to keep the 'we' coherent, even when borders are obscured. Especially when it came to notions of guilt and responsibility, all researchers found they had individual, yet mutually recognisable, reflections on working together in the research process.

Working the hyphen is not an exclusive task for the academic researchers. In this Collective Biography process, all six researchers explored the hyphen spaces together, each from their own point of view. Due to the nature of our research topics, however, the researchers who are experts by experience inserted the fragility of their personal experiences. Since these experiences are the very subject of the research, they felt they had less space for disengaging from the topics than the academic researchers. Disclosure of their experiences at times felt like disclosure of their own being, without the possibility to fully foresee the consequences of that disclosure. This fragility is an important topic to recognise and affirm when discussing topics close to the heart.

Building further on the notion that in inclusive research *"Self and Other are knottily entangled"* (Fine, 1994: p. 72) it is essential to recognise that inclusive research is not about application of new techniques or methods, but about endurance, about creating room for a high degree of reflexivity regarding distribution of power, and about being able to receive criticism and accept personal disturbances. This implies, however, that inclusive research demands engagement in unsettling encounters that involve people emotionally and personally (Church, 1995; Von Peter & Bos, 2020). Returning to our unease with the term 'co-researcher': our collective biography shows that there is a real risk of losing the connecting power that hyphen-spaces harbour, turning that same hyphen-space into a mechanism for disconnection.

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Chapter 5 – Cabriotraining

This chapter is based on:

Sergeant, S., Schippers, A., Sandvoort, H., Duijf, S., Mostert, R., Embregts, P. & Van Hove, G. (2020). Co-designing the Cabriotraining: A training for transdisciplinary (research) teams. British Journal of Learning Disabilities, 00:1, 1-16.

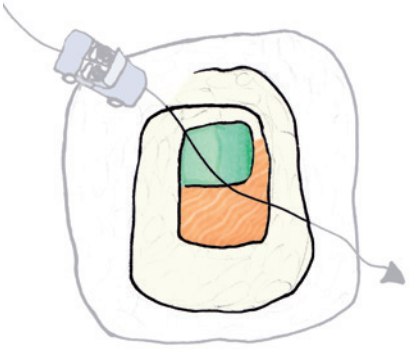

Figure 26: The Third Layer of the Sushi © Sanneke Duijf

In Chapter 5, I will focus on the third layer of the sushi, as depicted in Figure 26. We created the Cabriotraining based on our literature research and on the encounters with the (inclusive) teams we met.

5.1. Introducing the Cabriotraining

In Chapter 1, I bring together a number of identified advantages of inclusive approaches to research, to the lives of people involved and to the impact of research on society. Alongside I also introduce the challenges experienced by colleagues and ourselves whilst engaging in inclusive research. Analysing these challenges, I conclude in this dissertation that a training and coaching programme for the inclusive research team members can contribute to

- reflection on conditions and design of the research process;
- improvement of the communication;
- valuing of talents and knowledge of every research member;
- enlarging and enriching the research skills of all group members;
- the generation of new findings including more voices in the research work;
- the quality of the collaboration in every research phase of the research.

Figure 27a: Website of the Cabriotraining - Link

The training is developed in a first stage by Henriëtte Sandvoort and me. In 2020 we received extra funding from ZonMW to further develop and implement this training. We searched for companions and with this Cabrio-team (see Preface: introduction of the team) we managed to work out all of the six modules in a balanced programme.

Whilst developing the training and collaborating in our team, we started using the term 'transdisciplinary team' instead of 'inclusive team'. For clarity we need to point out to the reader the difference between interdisciplinary and transdisciplinary research.

> Interdisciplinary research is mainly seen as research in which experts from different disciplines work together on the same issue. (Groot & Klostermann, p. 23)
>
> In transdisciplinary research, scientists and other social actors strive to generate new knowledge in mutual interaction through a knowledge co-creation process. This can help clarify a complex problem and generate possible solutions. A characteristic underlying view is that the primacy of knowledge no longer rests solely with science. (Groot & Klostermann, p. 25-26)

In the conclusion section I will elaborate on why we decided to go from 'inclusive research' towards 'transdisciplinary research' in our language use (6.1.).

Figure 27b: Website of the Cabriotraining - Screenshot

Together with our Cabrio team member René Krewinkel, we created a website for our Cabriotraining[8] explaining why the training is developed, for who, how it is organised and what the content is about. Scanning Figure 27a will bring you to the homepage of this website.

The content of the training is structured in 6 modules:

- Module 1: Transdisciplinary collaboration in research
- Module 2: Reflection, self-reflection and intervision
- Module 3: Communication and rapportage
- Module 4: Multi-sensory presenting
- Module 5: Analysing together in research
- Module 6: Creative research methods

In the article 'Co-designing the Cabriotraining' we explain on the preceding research process and on the transdisciplinary collaboration.

[8] www.cabrio-training.nl

5.2. Co-designing the Cabriotraining

Accessible summary

The research was conducted by a team of researchers. Some of the researchers have experience of living with a disability.

- The researchers created training for other research teams that include experts by experience.
- The training has six parts. To decide what happened in the training, the researchers read articles and asked the research teams they trained about what problems they had and what they wanted to know about.
- The article tells why and how the training was made. It also says what training is needed for researchers with and without disabilities to learn and work together in a way that feels safe and useful.

In developing and providing the training, it was very crucial to search for a safe and welcome space for all people involved. As we don't know what is 'safe' for the other, this means we have to search together, in respect and with enough time to get to know each other.

Abstract

Background

Researchers collected questions and needs for training from 10 inclusive research projects in the Netherlands. Based on literature research and the information collected, six training modules were developed. Researchers sought to learn how to develop and provide training and coaching to inclusive teams on organising collaboration in the different stages of their research projects.

Method

An iterative training development process to support inclusive research projects was initiated by a researcher duo backed by transdisciplinary team including researchers, trainers and designers. Some members of the team have experiential knowledge based on living with a disability.

Results

Literature research resulted in four guiding theories, including Universal Design for Learning, Derrida's concept of Hospitality, post-materialist theory looking at agency as an assemblage, and Romiszowski's model situated within Instructional Design theory.

Insights gained during development of the training modules are documented with text, figures and vignettes. A core finding was the need to add 'Level Zero' to Romiszowski's model: a collective term created for all the interacting issues trainers had to consider because of research group diversity.

Conclusions

Hospitality formed the heart of 'Level Zero.' Creating a failure-free space for learning is an important pre-condition for the development and organisation of training. Training can inspire exploration and reflection on collaboration and can illuminate how to conduct research within transdisciplinary teams. Essential practices included working with nonverbal research methods, as these are (more) fit for purpose when including the knowledge of experts by experience and incorporating practice- and stakeholder-based knowledge.

Introduction

Historically, people with disabilities have lacked voice in many life domains, but in recent years, involvement of people with disabilities in life and in research has grown (Nind, 2011). This involvement in research is rooted within the academic field of Disability Studies and driven by the phrase *"Nothing about us without us"* (Albrecht et al., 2001; Kool & Sergeant, 2020; Schippers, 2018). Working together with the people the research concerns is also often framed as inclusive research (Frankena, 2019; Nind, 2014; Strnadová et al., 2014), collaborative research (Knox et al., 2000) or participatory research (Abma et al., 2019; Kidd et al., 2017).

The involvement of people with disabilities in research brings more perspectives into the research process, fosters growth within the research team (including both researchers with and without experiential knowledge), and enriches results (Frankena, 2019; Nind, 2014).

However, there are important pre-conditions for inclusive research. Research reveals that inclusive research teams need teambuilding, support and training to work together (Embregts et al., 2018; Nind, 2014; Strnadová et al., 2014). Strnadová and her co-authors explore not only the need of people with intellectual disabilities for research training, but also the importance of team-building as a *"crucial aspect of training an inclusive research team"* (Strnadová et al., 2014: 14), while Hood adds: *"It is not enough just to have people around; we need to belong"*. (Hood, 2014: 233, in Williams, 2018). Training and coaching can catalyse creation of spaces for belonging (Strnadová et al., 2014).

ZonMW –the Netherlands Organisation for Health Research and Development– demands that research teams it funds work in an inclusive way but reported lack of insight into the questions and needs these teams struggle with. Teams reported to our research group that journals and other funding organisations also demand inclusive research, but the teams

struggled with how to organise this, considering limitations in time and experience, and the complexity of their research work. Some teams communicated that their colleagues received training on working as an expert by experience, on presenting for the public and/or on social skills, which was highly appreciated and valued. However, to our knowledge, no training was available in the Netherlands for inclusive research teams that included all members of the research team. But what kind of training and support for inclusive research was needed?

The research described here was initiated by a researcher duo, and subsequently conducted with a team of experts from diverse fields working together with people with disabilities: experts by experience (see Section 2.1). Two designers are part of this team. Drawings created by social designer Sanneke Duijf (fourth author) for the research project are included in this article, illustrating how visual materials can help everyone access ideas. For our research project 'Working together, learning together', we were asked by ZonMW to bring together questions and needs from 10 Dutch research projects (see Table 1). Based on the questions and needs gathered, we started creating the training in an iterative process.

This article engages with the 'meta-how' research question: How can we develop and provide support, training, coaching to inclusive teams on how to organise collaboration in the different stages of their research projects?

In our work, we try to surpass binary thinking (them versus us) and writing (Brown et al., 2019; Schippers, 2018). We have expressed this as moving from 'being left in the dark' towards 'flying in the dark together' in Figures 28 and 29. By choosing this metaphor, we emphasise both the struggle and interest that 'flying together' (Figure 29) entails.

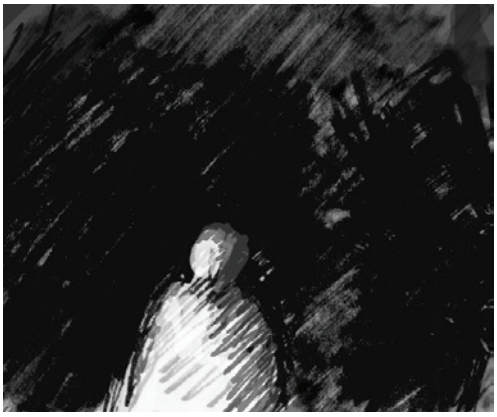

Figure 28: Being left in the dark © Sanneke Duijf

Figure 29: Flying in the dark together © Sanneke Duijf

Method

Participants and setting

Table 1: Overview 10 participating research projects

	10 research projects	Participants				
		JR	SR	EbE	Parent	SW
1	Improving QoL through sensory regulation for people with ID and autism	X	X	X	X	X
2	Supporting autonomy and decision making for people with ID and their allies		X	X		
3	Building a network of knowledge for people with acquired brain injury	X	X	X		X
4	Supporting social relations of people with ID through ICT	X	X	X	X	X
5	Supporting healthy lifestyle of people with ID through context and environment	X	X	X		X
6	Improving support in contexts of work, living and relations of young adults with mild ID and serious problems	X		X		
7	Developing training for inclusive teams	X	X	X	X	X
8	Creating a safer and more accessible world for people with multiple and severe disabilities through ICT	X	X	X	X	X
9	Creating insight in factors that have impact on the quality of the relationship between people with multiple and severe disabilities and their support workers	X	X	X		X
10	Defining the causes of the mental health and behavioural problems of people with ID displaying challenging behaviour	X	X	X	X	X

A researcher duo interviewed 10 research teams in the Netherlands, all supported by ZonMW. We asked them about collaboration within their teams. In Table 1, we provide an overview of the 10 research teams alongside our own research project 'Working Together, Learning Together' (the seventh project in Table 1). Projects 1-7 were funded by ZonMW in research call 1; projects 8-10 were funded in a second call 2 years later.

The training participants were very diverse, as depicted in Table 1, including junior researchers (JR), senior researchers (SR), experts by experience (EbE), parents and support workers (SW). In all training sessions, people with extensive research experience were trained together with people with no or little research experience.

When the duo started developing the training, they sought (a) complementary talents in designing training, creating figures, writing training manuals and (b) complementary

experiential knowledge. Ultimately, the duo created a team of seven people, including themselves (1 and 2 in the list below):

1. Female researcher, trainer and process supervisor
2. Female researcher, trainer and researcher with experiential knowledge
3. Male training developer/writer
4. Female social designer
5. Male designer and researcher with experiential knowledge
6. Female parent with expertise by experience
7. Female student researcher, Health Sciences.

The training was developed in an iterative process of reading, interviewing, creating training and coaching, giving training sessions, evaluating them, making adjustments and proceeding with the next interview sessions. Literature research remained important throughout the process, as summarised in Section 3.1.

The four phases within our study

The study lasted 4 years (2016-2020) and was comprised of four 1-year phases. In the first phase, we conducted literature research on the topic of inclusive research. We began with articles and reports already assembled by the research organisation Disability Studies in Nederland and used 'a snowballing method' inspired upon the method of snowball sampling and searching for key terms, primarily using GoogleScholar and ResearchGate, to locate additional sources. We sought relevant scientific articles but also more accessible material, like videos, cartoons, images and accessible texts to share with our research group and project staff we trained. We shared our findings through the DSIN website[9]. A selection of the findings on a memory stick was also shared with every research team at our introductory meetings. In the next phases, we expanded our exploration of theories and concepts underlying participatory methods, based on the questions and themes we came across.
Simultaneously, in this first phase the researcher duo conducted open interviews in introductory meetings with the first six research teams (see Table 1, Projects 1 to 6) to explore:

1. The content of their research projects;
2. Their collaboration with researchers, experts by experience and allies;
3. Training support needs, problems and dilemmas.

For these interviews, an accessible interview guide was prepared. Following each interview, findings were summarised in a Prezi presentation, which was shared with respondents for a member check. The Prezi also included a proposal outlining what training we felt could meet the needs expressed.

[9] https://disabilitystudies.nl/participatieve-onderzoeksmethoden

The introductory meetings took place at the very beginning of a research project. In some projects, we waited for training to start until the project was at full speed. Other teams asked us to start off with a team-building session (getting to know each other, discovering the talents and ambitions of the team members). Our work with the research teams included training, coaching, and in some cases 'presence', which meant being a communication or emotional support resource, offering immediate advice and providing an example of co-working to help experts by experience feel comfortable during research work. In phase two, we continued to explore needs in iterative cycles, whilst gradually building up a training and coaching programme based on the literature, models and theories we found. The researcher duo gave training sessions to researchers involved with Projects 1 through 6. All sessions took 2-3 hours, including informal evaluation with participants. Formal evaluation was conducted later. These evaluations were summarised in a logbook kept by the researchers. These logbooks were analysed (manuscript uploaded for publication) and used in the iterative development of the Cabriotraining. During phase three, the steps as taken in phase one and two were followed with three other research projects (see Table 1, Projects 8 through 10) bringing the total of projects to 10. In this phase, the researcher duo was part of a team of seven people (see Section 2.1). The enlarged team built up the training further in the fourth phase, based on their experiences of organising the training, the results of interviews with researchers from Projects 8, 9 and 10, the researcher duo's personal experiences of collaboration, and exploration of theory (see Section 3.1). By the time this article was written, the researcher duo had given 20 training sessions in diverse settings (see Table 1).

Procedure

Based on analysis of interview sessions, needs and questions from the inclusive teams, including our own project, were clustered. This process can be summarised as resulting in six overarching themes: belonging, self-awareness and competence-building, communication, sharing power, time and vulnerability. We worked to ensure that each thematic training module contained roughly an equal amount of material.

We were inspired by international research that highlighted issues like time, building relationships, talking things over, sharing skills and knowledge, shared purpose, reciprocity, training and teambuilding (Nind, 2014; Nind & Vinha, 2014; Strnadová et al., 2014). While gaining insight into the teams' questions and conducting literature research, we developed the meta-how question (Figure 30): how can we organise coaching and training for the teams on how to collaborate in inclusive teams? Our process of seeking answers culminated in the 'Cabriotraining' programme. We chose the name 'Cabrio' after making the introductory film[10] picturing the researcher duo working together to develop the training.

[10] https://www.youtube.com/watch?v=pOT2iRiEps4&t=1s

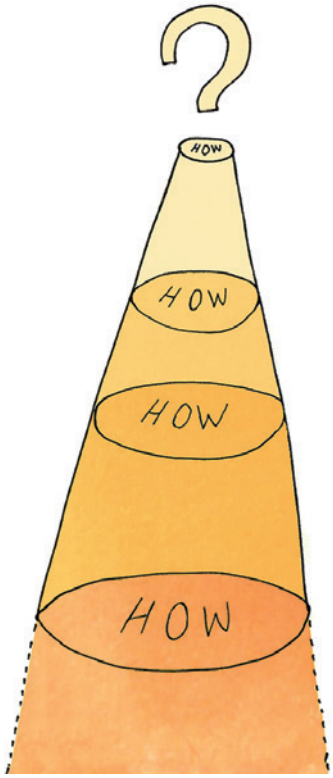

Figure 30: The 'meta-how' research question

The Cabriotraining modules were further developed into a more sustainable entity with support from the enlarged team in phase four. This team used an iterative process to provide solid answers to the detected and gathered questions, based on the conceptual frameworks (see Section 3.1), sometimes focused on the end goal, and sometimes zooming in on every single step of a lesson. The metaphor we used for this collaboration is 'creating a bridge while walking on it' (see Figure 31).

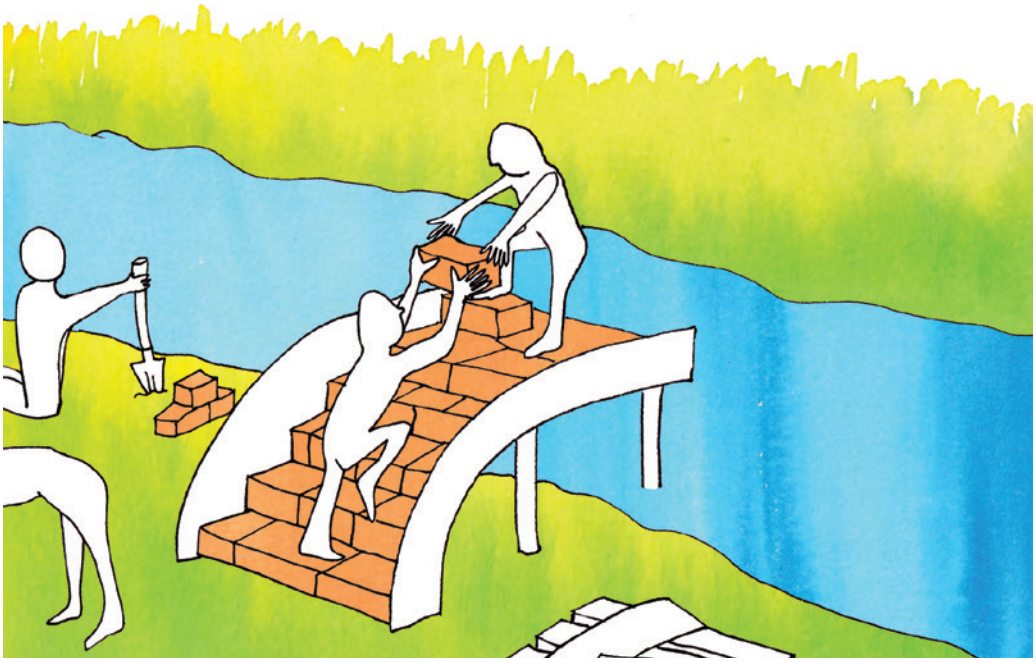

Figure 31: Creating a bridge while walking on it © Sanneke Duijf

Results

In Section 3.1, we introduce the theoretical framework developed via literature research to underpin development of the training programme. In Section 3.2, we provide a guided tour of the Cabriotraining modules and illustrate important findings from literature and the practice of organising and giving the training.

Results based on literature research

In the first phase (see overview of phases in Section 2.2) of our study, we started with exploring literature on Universal Design for Learning. From this framework, we branched out to explore more theoretical frameworks and concepts:

1. Theoretical framework 1: Universal Design for Learning (UDL)

- **UDL**

  Within our academic research field of Disability Studies, we do not focus on so-called 'reasonable adjustments' so individuals can participate, but instead strive for structural solutions and accessible contexts that take human diversity into account. This basic assumption that disability is always contextual is also inspired by the work

of architect Ron Mace on Universal Design, which he defined as "design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design" (Mace, 1985). The Center for Applied Technology (CAST) adapted this definition for learning environments to UDL in 1995, centring reflection on learning systems to meet the needs of all learners (Novak, 2019, in: Murawski & Scott, 2019).

Universal Design for Learning holds that students face barriers to learning not because of their own abilities but because of barriers presented by curriculum and schools. The UDL approach focuses on creating 'education for all', helping teachers and schools eliminate barriers through proactive design (Murawski & Scott, 2019).

- **UDL in the Cabriotraining**

  The UDL approach resonated as fundamental for dealing with the complexity and messiness of the learning environment we were developing, and for recognising and honouring diversity within the research groups. It helped us to reflect on our own experience and understanding of participants' training needs, and to have faith in the process of trying out, failing and restarting.

  In practical terms, the UDL approach necessitated that we prepared a welcoming environment. For people with autism the room had to be quiet, we had to create materials in easy language for people with intellectual disabilities, visual materials for everyone were needed, and researchers needed to feel safe during sessions with drama, music and painting. It focused us on presenting a 'research environment for all'.

  Frequently, research projects asked us to develop training only for experts by experience. We refused these requests, because we found that it was more interesting to learn in diverse teams. This does not mean that training diverse groups was easy. In Section 3.2, we elaborate on the design of the training and how diversity needed to be taken into account at every step. We found that it helps when the team of trainers is diverse, because then diversity is at the heart of design and organisation from the start.

2. Theoretical framework 2: Hospitality – Derrida

- **Hospitality**

  We built further on the UDL concept by connecting it with the work of Derrida on hospitality (Derrida, 1998). Derrida states that a hospitable approach does not last, and that something is expected at a certain moment: infinite unconditionality does not exist. One enters a process of searching and negotiating what hospitality might mean for each of us (Derrida, 1998; Sergeant & Verreyt, 2016).

- **Hospitality in the Cabriotraining**

  Trainees entered a space in which we introduced a process of creating meaning through disrupting dichotomies (Derrida, 1998). In the Cabriotraining, we tried to create a safe space where people felt they belonged and felt able to learn and contribute. This required an ongoing process of searching for what is safe for the other and for oneself. We needed to give participants opportunities to show and use talents in the training and in their research.

  In the Results section, the Vignette 1 illustrates how a safe environment can be created using the example of the Drawing Lab (Sergeant & Verreyt, 2016; Peels & Sergeant, 2018).

3. Theoretical framework 3: Looking at agency as an assemblage

- **Agency as an assemblage**

  To deal with the threat of tokenism in inclusive research (Nind, 2014; van Asselt-Goverts et al., 2017), we engaged repeatedly with what it means to work together in the academic field when coming from different disciplines, and together with people coming from non-academic backgrounds. These discussions revealed that all research group members found the feeling of belonging and the experience of being valued as a contributor important. Realising the importance of having time to build up trust and good work relationships, and creating adapted and safe work environments, encouraged us to place attention on giving and receiving capacity to use power and knowledge. This is reflected in the concept of agency as an assemblage, (Van de Putte et al., 2018), which is built on new-materialist theory. These authors dismantle the individualisation of agency: partners working together are seen as part of an 'assemblage' created through the interaction of diverse elements, including people, objects, qualities, speeds, flows and forces. Thus, inclusive research is not just 'placement' within the group: It is connection that leads to belonging and agency, to transforming a place into a space where everyone becomes a legitimate member (Van de Putte et al., 2018).

- **Agency as an assemblage in the Cabriotraining**

  In the Cabriotraining, we learned from this to take on 'success' and 'failure' as shared responsibilities. Trainers and trainees must search together for what helps and what is needed within the training and the research work. All members are part of a complex assemblage, working in close connection as legitimate members of a group. The concept of agency as an assemblage took us beyond UDL, which is often concerned mostly with ensuring places and materials are accessible. Belonging and comfort are relationship-based, and actively constructed within the assemblage.

4. Theoretical framework 4: Instructional Design (ID) – Romiszowski model

- **Romiszowski model**

  Romiszowski sees task analysis as the most important sub-activity in a contemporary education design approach. He pushes forward a design approach that consists of four levels. At each level, specific types of task analysis help designers make decisions about different components of didactic practice (Valcke, 2010).

  - Level 1: Why are we doing this? The first level is the project level, where the focus is on end goals, the general line of the instruction to be designed, and possible limitations.
  - Level 2: What are the bigger blocks of content? How are we going to build them up? This is the curriculum or course level, where people look for concrete objectives, structure and learning contents that are relevant to the total package.
  - Level 3: Instruction strategies in each phase of a lesson, and what media to use. This is the lesson-plan level, with emphasis on instructional events, the specific instructional strategies to use at every stage of the lesson.
  - Level 4: Zooming in at every single step/assignment, and interaction within a lesson. In this learning-step level, a script is delivered of the concrete learning and instructional activity, or the self-study materials that the learner ultimately receives (Valcke, 2010).

- **Romiszowski model in the Cabriotraining**

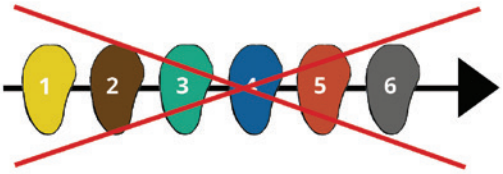

Figure 32: No linear model for developing the Cabriotraining © Sannek Duijf

Clustered questions and themes were used as the basis for building up training modules (see Table 1 and Figure 32) based on this model. It gave us scaffolding for the design of the Cabriotraining but was not too narrow and closed. It was helpful for breaking down the broad goals of the research projects, such as "How can we do better research in partnership with disabled people?", into steps that could be reflected in concrete training activities.

In our development process for the Cabriotraining, we bundled the lesson plans into a curriculum of six modules. In building up every module, we crossed the four levels

of Romiszowski's model. However, because we used an iterative development process, we did not develop the modules in a linear way (see Figure 32). In Table 2, we provide a brief overview of all modules and the themes they consist of. This structured table helped research teams to choose modules and elements they need. However, in Table 2 the modules look very separate from each other. This could lead to the conclusion that every module is a steady composition of immovable elements, but this is not the case. To explain this, we use the metaphor of 'the lap pool'. In a lap pool, the pool is divided into lanes with a cord, but if you dive underwater you can easily cross these boundaries and swim freely (see Figure 33).

In the actual training programme, we used a tailor-made approach, resulting in a non-linear model, as described in Section 3.2. To make the training work, training elements need to be chosen and combined, adjusted to suit the trainees, and made to fit the environment and time available.

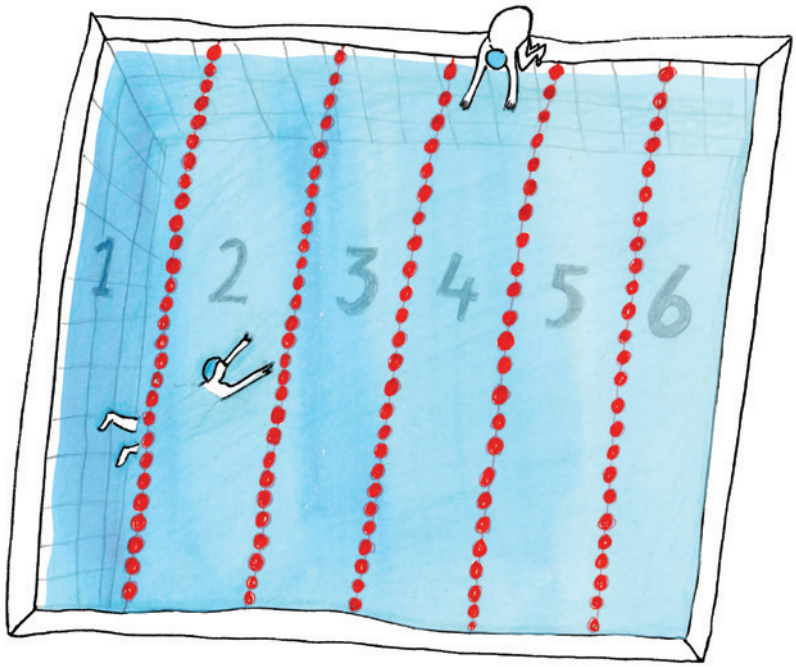

Figure 33: Cabriotraining with 6 modules, captured in the metaphor of a lap pool © Sanneke Duijf

TABLE 2: Six modules in overview

Module 1: Working together in research in 'a safe research environment for all'

- Introduction: Cabriotraining objectives
- What is research?
- Full citizenship: thinking about choice and control
- Quality of Life Model & Support Model
- The Citizenship Model and Inclusion
- Practice-oriented versus Theory-oriented research
- Quantitative versus Qualitative research
- Participatory research
- The value of expertise by experience
- Being a co-researcher
- Transdisciplinary collaboration in research

Module 2: Reflection on personal experience, needs and talents within the research team

- Me as a researcher
- Reflection and Self-reflection in research
- Talents and Qualities
- The model of 'Circle of Courage'
- The app 'Ebb'

Module 3: Communication in research work

- Universal Design
- Communication in research
- Reporting research results
- Reflection on communication between researcher and co-researcher
- Introducing Tableaux Vivants in report

Module 4: Creative research methods

- Why use creative research methods?
- How to choose creative research methods?
- What kind of creative research methods?
- Visual research methods, part 1: PhotoVoice
- Visual research methods, part 2: Graphic Elicitation: The Drawing Lab

Module 5: Analysing together

- Analysis in research is always teamwork
- Coding (scientific research)
- Theme analysis/Narrative analysis/Framework analysis/Pattern analysis
- Introducing Tableaux Vivants in research analysis

Module 6: Multi-sensory presentation

- Not just a presentation
- Learning to present
- Prepare a presentation
- My personal style in presenting
- Different ways of presentation: including all the senses

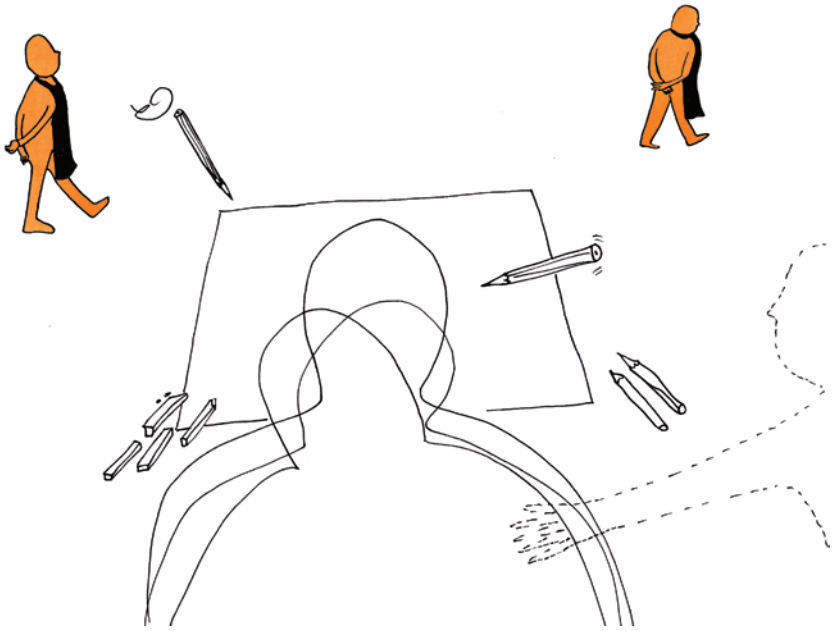

Figure 34a: Providing silent support within the Drawing Lab © Sanneke Duijf

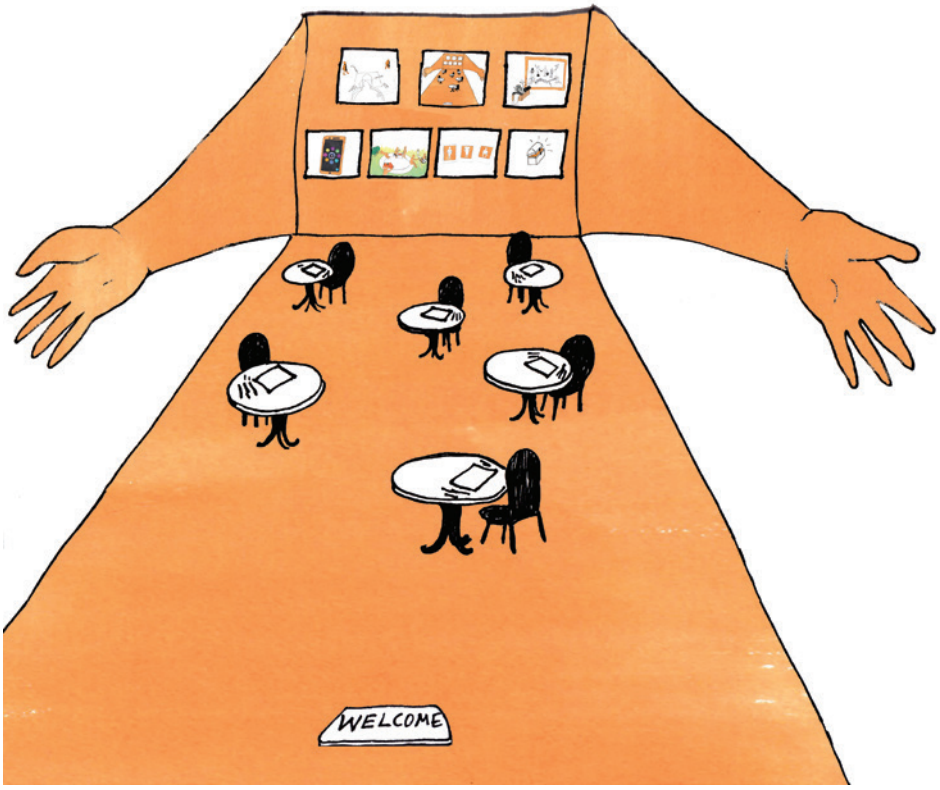

Figure 34b: Creating a safe space through a Drawing Lab © Sanneke Duijf

The six modules within the Cabriotraining

The six modules were based on both literature research and the clustering of questions gathered from the teams. In this section, we explore the modules, adding examples depicted in Vignettes. The Vignettes are all depicted in Figures and also explained in words, on the website of Disability Studies in Nederland (see links). These Vignettes show what training can look like, how safety and quality are ensured, how the training supports the learning goals of the modules, mistakes we have made, and the fluidity of the modules and elements depicted in Table 2.

Module 1: Working together in research in "a safe research environment for all"

The first module contains introductory lessons and training (see Table 2). Many teams asked for information on doing research in clear language for all research team members, and also wanted information on how to convince their funding organisations and directors to proceed with collaborative plans. However, research teams also asked for space to get to know their colleagues better, and teambuilding and intervision sessions. They often revealed poor insight into the talents and experience of their team members, their support needs, and how their collaboration could be organised. To initiate this exploration, we aimed to create safe spaces, as illustrated by Vignette 1 and in Figures 34a and 34b.

When people enter the room for the first training, they often feel insecure and stressed, leading to high arousal and less energy. People who have had bad experiences with school and training might worry about being able to cope. By making mistakes, we learned that although we thought we were being very hospitable, we did not know what hospitality means for the other. We learned to be very prepared and to welcome people, serve coffee and tea, provide lunch. Trainees felt comforted when the trainers were well-prepared.

We also learned not to strive for a 'perfect' training or perfectly smooth collaboration amongst trainers. In the feedback from trainees, we heard that being open and vulnerable about struggle was more supportive and educational than keeping up appearances (as we did when we started).

Vignette 1 - The Drawing Lab

The Drawing Lab* (Sergeant & Verreyt, 2016; Peels & Sergeant, 2018) welcomes a diverse group of people into a safe space where they feel capable of participating and contributing. People are invited to draw about what they find important in life. The Drawing Lab is based on the method of graphic elicitation. Each participant uses personal drawing language and may (optionally) explain the drawing orally afterwards. We discovered that the creation of space for non-verbal meetings, where people feel safe to share from their own experience—a way to interview people without asking questions—was as important as the method. In this way we retrieved stories from those people thought unable to share their experiences.

The planning of the Drawing Lab requires time and consistent organisation. It is very important to pay attention to every anchor in an organized way. Introducing creative methods asks for thorough reflection, and design of a well-prepared environment:

Before starting the Drawing Lab, we make all team members recognizable through the Drawing Lab apron. This step can be skipped in small groups.

The Drawing Lab team is given an oral and written introduction to the concept of 'Quality of Life' and the eight domains of wellbeing (Schalock et al., 2002). Team members learn to describe Quality of Life domains in a clear way to guests and get an introduction to handling the various steps in the Drawing Lab method. We practice the 'after-draw-interviews.' The Quality of Life framework is used as it is known worldwide and covers a broad field of important life themes.

- We explain the concept of 'silent support' to the team members (see Figure 34a): giving support to participants in a way that ensures they don't feel 'as if they need support,' as in this way they don't feel embarrassed.
- In the Lab, at least one artist is present who can help guests shape their ideas.
- In the room there is a table with information on Quality of Life and its eight domains in words, easy language, mind maps and images.
- Drawing pencils, crayons, fine black markers, eraser, pencil sharpeners, and white paper in small and large formats are displayed. The materials look professional to make sure people don't feel treated in a childish way.
- The drawing tables are set up criss-cross with comfortable chairs.

To obtain a safe space (see Figure 34b), appropriate ways of communicating must be found. In the Drawing Lab, we use spoken and written words in easy language. We also use photos and figures to explain the Drawing Lab assignment.

* In previous research, we created the Drawing Lab based on the experience of organizing eight drawing labs in five different settings (Drawing Festival 'The Big Draw,' Music Festival 'Rock for Specials,' Disability Studies Congress, Congress for experts by experience, Congress on the UNCRPD). This new approach was designed to organize graphic elicitation in order to facilitate and support dialogue on Quality of Life themes. It was tested over four years with 551 participants, including at least 198 people with intellectual disabilities.

Figure 35: Vignette based on extracts from personal research diaries

Module 2: Reflection on personal experience, talents and needs within the research team

In the second module, we focused on the talents and qualities of each individual. It is only by knowing your strengths and those of the others that you can use them in the best possible way. An example of how to investigate individual talents and strengths can be found in Vignette 2 and in Figure 36a.

Figure 36a: Creating a space for reflection, dialogue and intervision through the app Ebb created by René Krewinkel

Vignette 2 - The Ebb app

We developed an electronic application (app) named Ebb (https://ebb.works). Ebb can be found for free in the App Store and in Google Play. Ebb contains a database with photos and with drawings from the Drawing Lab and can be enriched with the participant's own drawings and with photos. We used the Ebb portfolio to catalyse reflection on 'Who am I?' and 'What do I find important in life and work?'. The app creates a failure-free environment (with images) in which people feel safe (at home, in their own time, on their own device, by themselves) and facilitates belonging through the opportunity to share with others during training.

Inspired by the work of Wang and Burris (1997) on PhotoVoice, we agree that the lesson a picture tells us is not in its physical structure, but rather in the way people interpret the image. We found that most people elaborated on their pictures with enthusiasm. Of course, some people with an intellectual disability were not able to speak about their drawings. For people who are non-verbal, the app is also a methodology that understands images as a data source in their own right (Black & Warhurst, in Saunders & Tosey, 2015).

Ebb is based on PhotoVoice, photo-elicitation and graphic elicitation. These visual methods enable participants (1) to record and reflect on their lives, (2) to advocate for changes in their lives and (3) to participate in research (Overmars-Marx, Thomése & Moonen, 2016; Fullana, Pallisera & Vilà, 2014; Sergeant & Verreyt, 2016).

However, for people with visual impairments, Ebb is not a very helpful way of reflecting and sharing on identity and talents. Also, some (older) people had no device to download it to or found it difficult to work with. Some people needed assistance to use the aWhen the method seemed inappropriate, we presented other means, such as printed photos, or objects that can be touched, felt and collected in a box.

Figure 36b: Vignette on Module 2

Figure 37a: Tableaux Vivants – inspiration trunk © Sanneke Duijf

Figure 37b: Tableaux Vivants © Sanneke Duijf

When the expanded Cabriotraining team with researchers, experts by experience, support workers and parents worked together on a project, each person added value to the research from their own field of knowledge and experience. Communication within and from the team therefore needed to be rich in variety and design. We supported people to use verbal and written language, easyread materials, images, mind-mapping and so on. While written documents are often the main form of communication in research, this module focused on more diverse ways to communicate and report within and outside your research community; see for an example (the use of Tableaux Vivants in report) in Vignette 3 and Figures 37a and 37b.

We tried to inspire researchers to communicate and report through all senses. We learned to build this up slowly and to not start too far from their comfort zones.
We had not realised how uncomfortable 'stepping out of the verbal box' can be for academic researchers.

Vignette 3 - Introducing Tableaux Vivants in report

'Tableaux Vivants' is French for 'living pictures.' Historically, a cast of models represented scenes from art, literature, history, or everyday life on a stage. After the curtains went up, the characters posed silently and motionless. Often a large wooden frame depicted the perimeter of the stage, referencing the frame of a painted canvas (Tortello, 2011).

In the Cabriotraining we embedded Tableaux Vivants to explore the meaning of data in the analysing phase. It sparks discussion in a playful, interactive way, but also gives research teams a way to share their roles and relations.

In this assignment, we put a trunk in the room. The trunk is filled with costumes and props. We invite participants to choose one or more items, then explain why they picked them: What do those elements remind you of, what does a costume tell me about you? The participants are then asked to search for body and facial expressions that support these meanings. Relations with others are explored in building up the tableau vivant. When the tableau is made, people are asked to freeze, and a picture is taken. The picture can be placed in a golden frame and embedded in presentations, but the live performance is more powerful.

An advantage of the assignment is that participants may feel less anxious about taking part in a silent group activity than about presenting orally in front of the public (Tortello, 2011). However, it requires guidance from an experienced workshop trainer. We also learned to implement 'Tableaux Vivants' only when trust is established in a group and people feel comfortable exploring creative assignments.

Figure 37c: Vignette on Module 3

Module 4: Creative research methods

We explored with training participants how to collaborate in research, how to collect more diverse data, and how to include people with intellectual disabilities and others who are non-verbal or less comfortable using verbal language in research. We tried to inspire teams to enlarge their suitcase of research methods. We reflected in the Cabriotraining on how implementing Universal Design can make your research stronger, richer and open to more people.

Figure 38a: Treasure box © Sanneke Duijf

We learned to encourage people to think more creatively without making them feel their current quantitative or qualitative research is less interesting for collaborative research: instead, they can benefit from adapting methods they already know. See Figure 38a and Vignette 4 for an example.

We go from this treasure box towards exploration within the visual arts (still images, moving images, 3D artefacts), performing arts, literary arts and the multiple methods approach (Coemans & Hannes, 2017). The most frequent questions are about PhotoVoice and Photo elicitation. Often, we start from there and try to inspire participants to make a little stepNtowards exploration of other, less familiar creative methods.

Vignette 4 - Encouraging researchers to use creative research methods

Participants sit in a circle. In complete silence, a treasure box is passed from person to person. We explain that inside the treasure box the secrets to good research are hidden. Each participant is asked to take a look inside the box without the others looking over their shoulder. Inside the box is a mirror, so they see… themselves. We start the session on exploring creative research methods with thinking about ourselves and our experience, talents and temperament, because researchers need to feel confident and comfortable in embedding a creative research method into their work. Starting off with the treasure box, we open the discussion about who feels confident with photography, music, theatre or any other art form, and we open up the possibility for sharing no interest or trust in this kind of research work, without judgement.

Figure 38b: Vignette on Module 4

Module 5: Analysing together

Based upon the work of Nind (2011) and our own experiences, we state that analysing in an inclusive team is challenging but realisable. In the Cabriotraining, we try to inspire teams to also collaborate on analysis. We noticed that many teams that collaborated with people with no or less experience in doing research, people who are less verbal, or people with intellectual disabilities, need this inspiration and exercise. We learned that it is very useful—if possible—to start with realistic data materials delivered by the trainees.

Thus, this module is best delivered after data-gathering. From there, we ask the research teams how they conduct analysis, then search together for ways analysis can be more collaborative.

The more diverse the data are, the more options you have for analysing together, as illustrated through Figure 39a and Vignette 5.

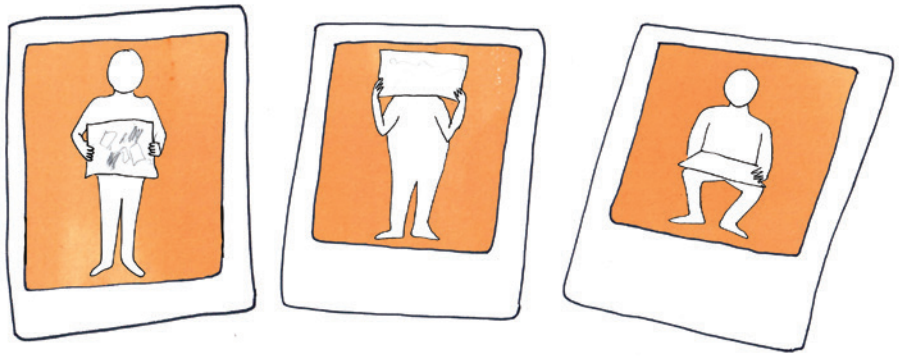

Figure 39a: Engaging with data in analysis © Sanneke Duijf

Vignette 5 - Engaging with data in analysis

This assignment is introduced in the Cabriotraining to inspire research teams to conduct inductive thematic analysis, beyond the use of only text and verbal language. Research team members are asked to send their data in beforehand, as words and images. We make large copies and spread them around the room. Team members cut out from interviews, photos that touch them in any way. Each participant then creates his or her own collage with parts of the original raw data and presents it in such a way as to tell something about the content. Afterwards each person gets the opportunity to talk about his or her work, but the photograph of the person with the collage, and the collage work itself, are already outcomes of the engagement with the data.

People who have less experience doing research become more confident about engaging in analysis through this exercise and help other researchers to understand and interpret data from different angles.

Figure 39b: Vignette on Module 5

Module 6: Multi-sensory Presentation

The sixth module invites the participants to join in different forms of presentation. Again, here we noticed the danger of going too fast in exploring multi-sensory forms of presentations for researchers in the academic field. We learned to start close to what researchers are familiar with, then slowly try out more forms of presentation.

In the Cabriotraining, we stimulated research teams to collect data in various forms: drawings, interviews based on questionnaires and dialogue/focus groups, photographs, collections, video, observations. The richness and diversity of these materials can be expressed by creating a film, dance performance, theatre play, PowerPoint or Prezi presentation, painting, photograph collection, catalogue, hands-on workshop, etc.

In challenging research teams to explore the diversity within the presentation modes of their research work, we encourage all members of the research team to find a way to be able and feel safe with the presentation of the results of the collaborative research work.

In Vignette 6 illustrated with Figure 40a, you will find a time-consuming but very inspiring example: team members confirmed this assignment involves more people in planning presentation and ensures more members of the public can grasp the essence of their research.

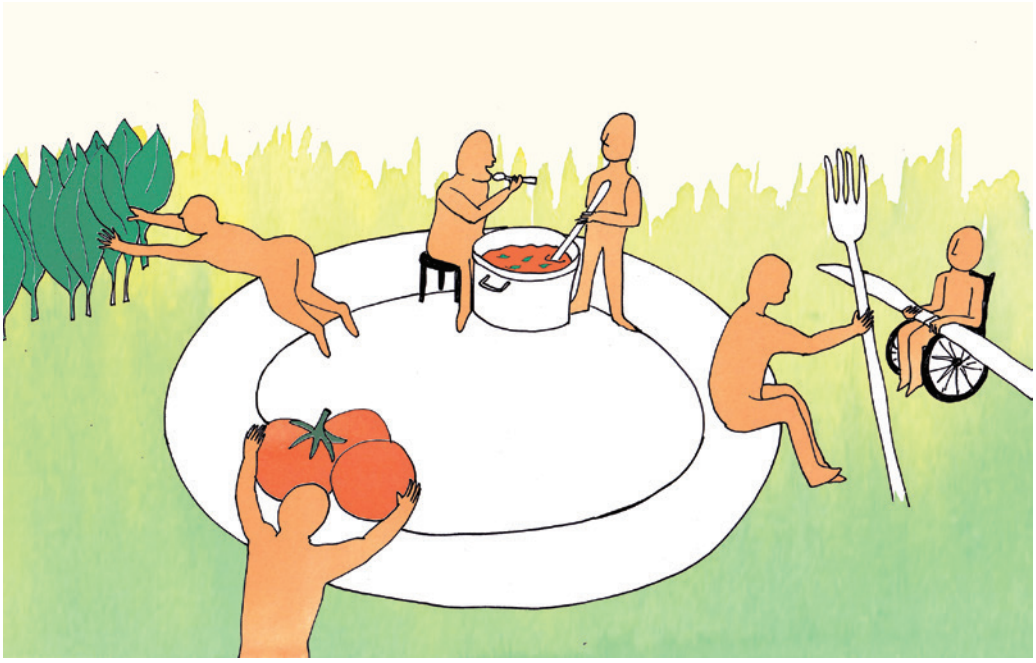

Figure 40a: The Research Kitchen © Sanneke Duijf

Vignette 6 - Introducing the metaphor of the 'Research Kitchen' in presentation

In the Cabriotraining we use the analogy of The Research Kitchen: Who is in the Research Kitchen and what are they doing? Who gets the ingredients and who does the cooking? Who leads and who follows in these processes? Who is here all the time, and who flies in and out? Who serves the food, and who stays behind to do the washing-up?

In thinking about how to present collaborative research results, we invite people to think about a dish, flavour or ingredient that explains the content of the research. The research group has to collaboratively search for ingredients and organize the cooking. The interesting thing about this assignment is that it catalyses collaborative work, and at the same time it is a team-building exercise that defines roles.

In organizing a presentation, the team is asked how to invite the public to 'smell and taste' their research content.

Figure 40b: Vignette on Module 6

Level Zero

In building up the six modules, we were always engaging with questions and themes, and connecting with theories (see Section 3.1). Circling around these questions and complexities made the structure feel messier. Finally, we found a solution for this 'problem': identifying it, naming it 'Level Zero'.

Figure 41: Level Zero: Space for search and reflection © Sanneke Duijf

Adding 'Level Zero' to the linear model of Romiszowski took us 4 years and forms the heart of our research results. In Figure 41, we present Level Zero as a space and source for questioning and reflection on Universal Design, Derrida's concept of hospitality, the concept of agency as an assemblage, and Romiszowski's model itself.

Level Zero is our collective term for all the interacting issues we constantly had to be aware of. Because of diversity within the research groups we trained, we had to be prepared for very different learners, with different backgrounds and learning questions.

Therefore, the Cabriotraining is not a fixed programme. It leaves space for the personal experience and knowledge of the trainers and trainees. To honour this complexity and fluidity, in Level Zero we acknowledge that being aware of diversity and taking it seriously without judging and categorising people is fundamental. Here, we learned from the UDL theory and practice elaborated on in Section 2. Level Zero keeps us from proceeding in the same linear way, giving depth, breadth and multi-applicability to the training. Figure 42a demonstrates how we built up the six modules. Each time we connect with Level Zero, and at the same time, we align with content from the other modules. This allows us to switch between modules and to work in an iterative way. In Figures 42a and 42b, the modules have been colour-coded; these colours were also used in the design of the training materials.

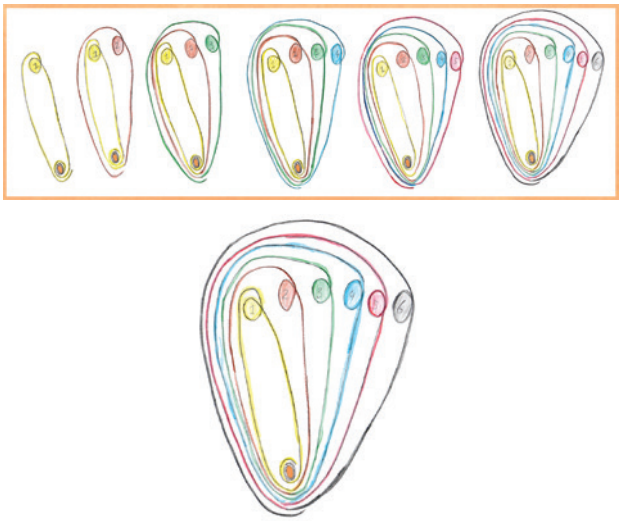

Figure 42a: Making a non-linear model by adding level 0 © Sanneke Duijf

Figure 42b: The fan-shaped Cabriotraining model © Sanneke Duijf

We summarise in figures how we created every module, depicting them in the form of a mussel. Within the first module, we worked from phase 1 to 4 of the Romiszowski framework, building further on awareness and questions raised in Level Zero. This is made visible in Figure 43. More modules can always be added.

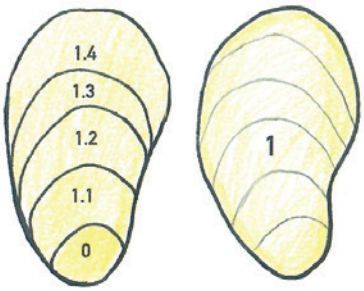

Figure 43: Building the 'mussel': Module 1 © Sanneke Duijf

Conclusions: Five lessons learned

In this article, we engaged with the research question *"How can we develop and provide support, training, coaching to inclusive teams on how to organise collaboration in the different stages of their research projects?"* We conclude the results section with the following five lessons learned:

1. We worked as a team on this complex social issue of providing training and support for research teams in a safe environment, based on their questions and on theory. Decisions were made jointly. Together, we filled a backpack for inclusive training teams. Trainers can pick from this backpack items that relate to the people and questions they encounter.
2. Creating failure-free spaces for learning is an important pre-condition for successful use of the training materials. As in the example of the Drawing Lab (Vignette 1, Sergeant & Verreyt, 2016; Peels & Sergeant, 2018), the failure-free space where it takes place is a requirement for the method of graphic elicitation to work. Searching for what hospitality means to all involved is part of this, crucial in the development and organisation of the Cabriotraining, and is the heart of Level Zero.
3. We learned that 'the process defines the product': searching together for what is needed ensures that training will be supportive and helpful. We tried to be transparent about the strategies, methods, actions and experiences used in this process of building up the Cabriotraining. Giving insight into the process of developing the training is the core of our results, as summarised in this article.
4. We created training for inclusive teams because we learned that there are many opportunities for everyone to learn, individually and collectively.
5. We found that non-verbal research methods, creative methods and arts-based research methods offer solutions that are more fit for purpose, and elicit the knowledge of experts by experience, practitioners and stakeholders (Coemans & Hannes, 2017; Van der Vaart et al., 2018).

Discussion

After summing up our conclusions, we return to our theoretical frameworks and concepts, and the questions and dilemmas the research results presented. We outline strengths and limitations and offer suggestions for future research.

Universal Design

Our work confirms that training for inclusive teams is needed (Strnadová et al., 2014) but conditions must be taken into account (Embregts et al., 2018; Nind, 2014). Creating safe, failurefree spaces where all people involved in the research (junior and senior researchers, people with disabilities and their allies) belong is crucial for training sessions and in research itself (Williams & Moore, 2011). Further research involving more diverse inclusive research projects is needed to explore optimal conditions for failure-free spaces, acknowledging differences and communalities. In future research, we also want to explore trainers and their influence on outcomes.

Hospitality

We learned that we never know what hospitality for the other means (Derrida, 1998). For inclusive teams, the process of exploring what team members need in order to feel safe belong and contribute is an important element within the Cabriotraining, and needs further exploration, particularly regarding conditions that catalyse a sense of belonging and safety to speak up or to disagree. It was evident that creating space and time for all research members to reflect, dialogue and explore new methods and strategies in collaboration was important.

Investing in skill development of experts by experience and at the same time exploring new ways of doing research is an important outcome from our Cabriotraining experience and literature research (Abma et al., 2019; Embregts et al., 2018; Frankena, 2019; Heessels et al., 2019; Jongerius et al., 2014; Kidd et al., 2017; Knox et al., 2000; Nind, 2011; Nind & Vinha, 2014; Strnadová et al., 2014). Academic researchers also often lack experience in collaborating with people with disabilities, applying non-verbal research methods, and establishing safe research environments (Nind, 2014; Nind & Vinha, 2014; Strnadová et al., 2014).

Looking at agency as an assemblage

In the creation of the Cabriotraining, a group of researchers, experts by experience and social designers started working intensely together as social active agents for strategic change (Raein et al., 2013; Van de Putte et al., 2018). It became clear that working cooperatively with stakeholders made the process complex, because we spoke different jargons, the road was unpredictable and the outcome unsure. The process was also exciting, because sometimes we worked apart from each other: solo or as a duo. We

experienced moments in our collaboration where we felt strong autonomy, and others where we felt very entangled, dependent but also vulnerable (Thorpe & Gamman, 2011). Further research is needed on how to guide this process of co-creation without losing people because of this intensity and unpredictability.

Instructional design – Romiszowski model

> *"'Training' is akin to following a tightly fenced path, in order to reach a predetermined goal at the end of it. 'Education' is to wander freely in the fields to left and right of this path – preferably with a map."*
>
> (Romiszowski, 1981, p. 3)

We illustrated with the lap pool metaphor how fluidly the Cabriotraining elements can be placed, replaced, combined and skipped. You could call it *"a field in which you can freely wander in",* building further on Romiszowski's definition of education (see Figure 44).

Figure 44: To wander freely in the fields © Sanneke Duijf

This brings us to the term 'training'. We noticed that the first questions from research groups were often rather technical: we want training on how to give multisensory presentations, how to analyse together, to elaborate on 'what is inclusive research?', etc. After a few sessions, research groups often asked for more intervision (peer coaching) on collaboration and managing struggles. Accordingly, we decided to organise intervision, coaching and teambuilding.

To conclude, training and education are intertwined in the Cabriotraining (Romiszowski, 1981; Valcke, 2010). Future evaluation is needed to examine the qualities and the weaknesses of the Cabriotraining approach.

Level Zero

Introducing Level Zero into the model of Romiszowski (Valcke, 2010) taught us that we will never know in advance what good training consists of. We will always be searching and trying. Level Zero helped us to build a model that is fluid, dependent on context and society. What matters and what is needed will become clear through dialogue between trainers and participants. It is not about what we think you should learn, but about what we have to learn together, is an analogy we used in our 'Research Kitchen', inspired by the work of Paul Bocuse, Eric Broekaert (Broekaert, 1989) and my own family history. The trainers, environment and society all have agency (Van de Putte et al., 2018). We are all taking part, influencing and learning in this process (see Figure 45).

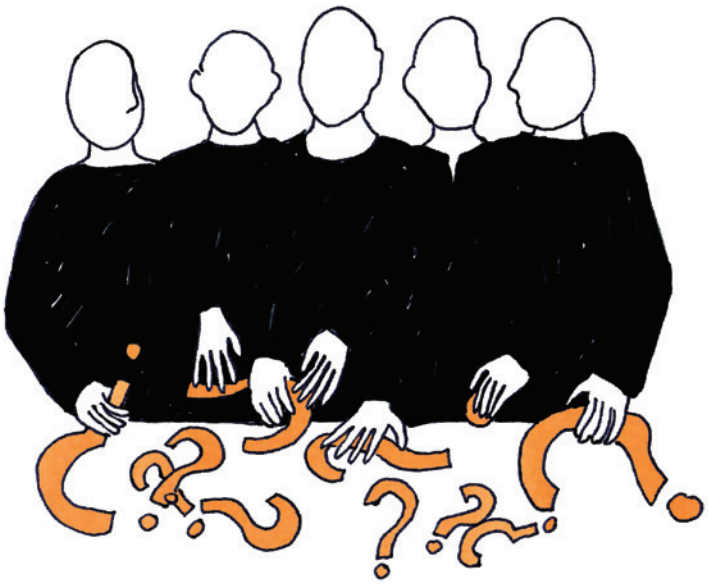

Figure 45: We all have agency © Sanneke Duijf

Returning to Level Zero helped us avoid binary thinking. As we proceeded with our research, we were increasingly convinced of the problem behind the word 'inclusive', which still encloses a dichotomy: we (academic researchers) and them (people with disabilities). 'We' decide about the conditions on which 'they' can join us in research. Iris Young makes a useful distinction between two forms of exclusion: external exclusion, which is about how people are kept out of the process of discussion and decision-making, and internal exclusion, where people are formally admitted but not taken seriously (Biesta, 2019). Inclusion is often defined as the process of those who are already inside bringing in those who are outside

(Biesta, 2019), making outsiders into insiders. Rancière critiques this as a colonial way of conceiving democratisation (Biesta, 2019), for example, stating that democratisation is not a process that starts in the centre and spreads to the margins. Rancière points out that inclusion should not be understood as adding more people to the existing order, but as a process that necessarily involves transformation of that order. The impulse for this transformation does not come from within, but from outside (Biesta, 2019).

We agree with Young, Rancière and Biesta that inclusion is not simply the process of including a group that was previously excluded. It is the formation of a group with a specific identity that did not exist before. Chalachanová et al., (2020) have focused on the relational aspects of successfully working as what Carroll (2009) has called 'alongsiders'. They note that successful relationships between researchers with and without disabilities take time to build, as partners may have issues with trust, communication, handling disagreements and defining roles. Once our research group was formed, we searched for a concept that supported our experience of working together. We found it in the concept of transdisciplinarity. Transdisciplinary research can be defined as collaboration between science and social actors within society in knowledge co-creation (Groot & Kloosterman, 2009). Experts from diverse fields work together with people within society (experts by experience) to tackle complex social issues (Bunders-Aelen et al., 2010). Crucial in this transdisciplinary research, knowledge development, collaboration and knowledge co-creation is the form of cooperation between society and science, in which the primacy of knowledge no longer lies solelywith science (Groot & Kloosterman, 2009). Bernstein (2015: p. 1) states that *"Transdisciplinarity today is characterised by its focus on 'wicked problems' that need creative solutions, its reliance on stakeholder involvement, and engaged, socially responsible science"*. This is very pertinent to issues concerning researchers with expertise by experience.

However, it remains difficult not to think in terms of 'them' and 'us'. We hope the Cabriotraining can inspire researchers to be curious, to connect with others and to create failure-free environments, collective spaces for connection, reflection, reciprocity and hospitality. As we looked back at the frameworks that underpin the Cabriotraining programme, we found they relate to each other in specific ways. Some were more fundamental for our work, others more practical. As expressed in Figure 46, the different theories form layers that connect to create a whole. The theoretical frameworks inspired the development of the training as a multi-layered entity.

Figure 46: Building up theory © Sanneke Duijf

Strengths and limitations

The strengths of our approach can be summarised as follows: the Cabriotraining was developed by a researcher duo who have worked successfully together over a long period of time, plus additional team members and support. We were able to draw on, critique and extend theoretical frameworks that underpinned our work, and found a receptive audience amongst the teams trained. The training elements were built up through a process of continual testing and development and are flexible and open for use by others.

We only have experience in training teams that include researchers labelled as having intellectual disabilities, autism and acquired brain damage. This experience gave us the possibility to work with people who are often seen as people who lack cognition, concentration, communication skills and abstract thinking. We are aware that some experts by experience are asked frequently to take part in research (Beresford, 2013), whereas people who lack literacy skills, competence in interviewing or in data analysis tend to be excluded from doing research (Beresford, 2013; Nind, 2011). This practice risks excluding many people. In future, we want to work on further diversifying our pool of researchers. Research on how people with severe intellectual disabilities and other excluded groups can join inclusive research communities is needed.

This article does not reflect evaluation of how participants perceived the training. Formal evaluation is ongoing and will be the topic of another article. Finally, the Cabriotraining relies heavily on in-person contact. When the Coronavirus pandemic arrived, it disrupted our work. We have placed resources and information online[11], but experience tells us that

[11] www.Cabrio-training.nl

disabled people rarely have equal facility with or access to digital technologies. This introduces fundamental inequalities that are not present when we work in a fully accessible way.

Postscript

After introducing the Cabriotraining at the University of Bristol in March 2019, we received a short text from Artemi Sakellariadis, Director of the Centre for Studies on Inclusive Education (CSIE) in Bristol. We want to conclude with her beautiful words:

Them and Us
slowly becoming We
Including every day
those who habitually
were left out
No more gagging
by implied hierarchies
No more put-downs
Towards fellow human beings
Who are differently abled
Learning from each other
Genuinely learning
From each other

Acknowledgements

We want to thank the Cabrioteam for the inspiring work together. Our gratitude goes also to all the teams we have met. Thank you for your trust, openness and collaboration. Our last thanks goes to ZonMW—the Netherlands Organisation for Health Research and Development—for making the research work 'Working Together, Learning Together' (Dossier Number: 845001004) possible and for encouraging and supporting the work of many transdisciplinary research projects in the Netherlands.

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5.3. The Cabriotraining

Building up the Cabriotraining in an iterative process, based upon literature and experience, brought us in the third layer of the sushi, meeting many projects within the National Programme 'Gewoon Bijzonder'.

As already mentioned in the introduction, our research project is funded by ZonMW and aimed at exploring the participation of people with disabilities within the National Programme 'Gewoon Bijzonder' research projects. 'Gewoon Bijzonder' can be translated as 'Typically Special'. Henriëtte Sandvoort writes in her column on inclusive research we should move on to 'just research' staying away from 'special' (Sandvoort, 2019, September).

In 2020 we created the website www.Cabrio-training.nl. On the website we give oversight in plain language, photos, film and drawings on

- The why, how and what of the training;
- The Cabrio-Team;
- The publications on the Cabriotraining;
- All the Modules and the Handbook we developed (for trainers and registered participants.

On our website we also tried to stay away from 'special' introducing the Cabriotraining as a training for teams which consist of a variety of people: people with scientific background, people with disability expertise, professionals, artists, designers, …

5.4. References

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Chapter 6 – In conclusion

Our research work gives insight to the wickedness of inclusive research (Figure 47) revealing no simple answers and unambiguous conclusion. Therefore, I named this chapter 'In conclusion': it will remain 'work in progress' as we made clear in Chapter 5 with the concept of Level Zero.

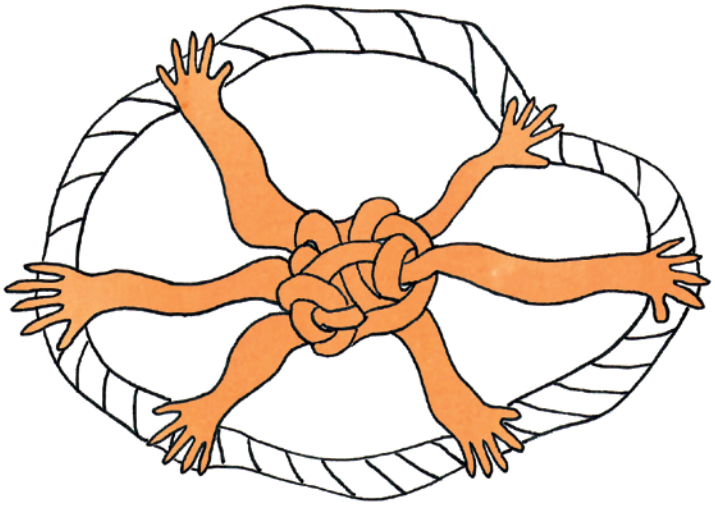

Figure 47: Wicked Problems © Sanneke Duijf

Chapter 6 brings us to the fourth and last layer of our sushi model as depicted in Figure 48. This layer captures all encounters: the close connection as researcher duo, the collaboration with the other duos in the Collective Biography, the development of the Cabriotraining with all the research teams and all the formal and informal meetings we experienced in the last four years.

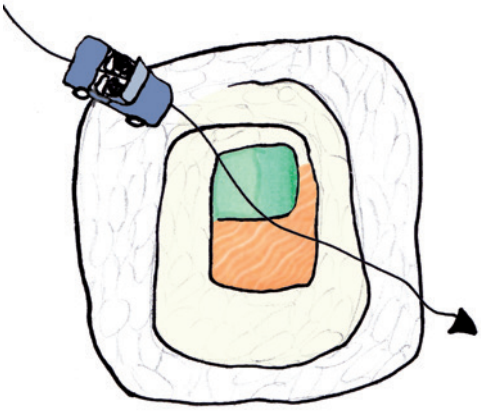

Figure 48: The Fourth Layer of the Sushi © Sanneke Duijf

6.1. Main findings

The aim of this study was to contribute to HOW inclusive research can be done. On the road we moved from calling ourselves 'inclusive' towards framing ourselves as a 'transdisciplinary team' (Chapter 5: Co-desiging the Cabriotraining) . With this team we aimed to gain insight into the themes, dilemmas, problems and catalysing processes within transdisciplinary research projects, including our own project and from this experience to develop training for the teams. The teams who received the training mostly acknowledged the reasons for conducting inclusive research (Nind, 2016) are clear and defendable:

- offering different perspectives;
- helping to ensure that research priorities are important and relevant;
- measuring outcomes that matter;
- helping to recruit experts by experience for research projects;
- helping access hard-to-reach groups;
- assisting or controlling dissemination and use of findings;
- becoming empowered through taking part;
- becoming engaged in the politics of service change.

Therefore, in our research work and in our trainings we did not focus on the WHY-question of inclusive research. Our research focussed on HOW to bring this goal to fruition in daily practice: *"How to bring good science and good inclusive research practice together?"* (Nind, 2016, p. 189). That is why we started exploring the questions and dilemmas in the teams we encountered along with creating the Cabriotraining embedding identified factors that were important to relationship building according to Nind and Vinha (2014): talking things over, sharing skills and knowledge in working things out, sharing a purpose, spending enjoyable time together and opening up new opportunities for each other. Our training offers methods identify and deal with differences in power and experience, reflection on collaboration and joint research work. Table 3 provides an overview of the results and outputs of the studies in this thesis in relation to the two research questions:

1. What are the catalysing ingredients and conditions for organising inclusive research in order to overcome attitudinal barriers, barriers in the social process, material barriers and within-person barriers?
2. Based upon these ingredients and conditions: what kind of training and coaching is needed?

Within our research we started with exploring ingredients and conditions for inclusive research. In this exploration (Chapter 2) four conditions surfaced. From this analysis we concluded to further explore two conditions in subsequent studies namely (*) multi-sensory communication and research methods (Chapter 3) and (**) engagement in reflection (Chapter 4). The results of this exploration were all included in the development of the Cabriotraining (Chapter 5).

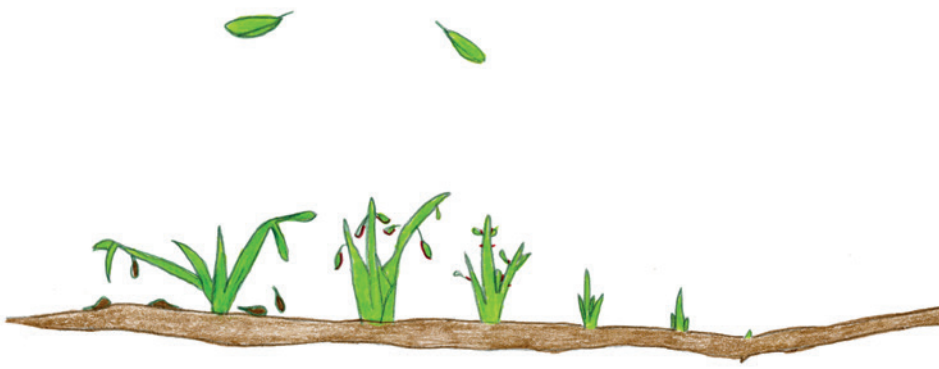

Table 3: Summary of results

Research questions	Results	Discussed in
Research question 1: What are the catalysing ingredients and conditions for organising inclusive research	Identified conditions for inclusive research: - Safe research spaces / Belonging - Room for collaborative learning & Competence building - Multi-sensory communication and research methods (*) - Time for reflection on (**) ° Power / ownership / vulnerability ° Prejudice / stigma ° The risk of tokenism	Chapter 2 – On the road Study
Research question 1*: Exploring the condition of multi-sensory communication and research methods	Using imagery in research and dialogue: Identified qualities: - Leitmotiv - Ambiguity - Choice - Revelation - Distance	Chapter 3 – Creative research methods Painting Pictures Study
	Using creative methods in disability studies research: Identified challenges and qualities: - Embodiment - Discomfort with messiness - Connection - Plurality of voices	Chapter 3 – Creative research methods Post-Roundtable Study
Research question1**: Exploring the condition of engagement in reflection	Engaging in reflection on working relationships in inclusive research: Identified learnings and insights: - Necessity of permanent meta-conversation - Construal and maintenance of 'we' - Handling dilemmas in responsibility	Chapter 4 – Collective Biography on Collaboration Study
Research question 2: Contributing to HOW inclusive research can be done: What kind of training/coaching is needed	Product: The Cabriotraining including - 6 modules - the app Ebb - the Drawing Lab	Chapter 5 – Cabriotraining Study

Now we have given overview and summary of our results, we will move on our findings, trespassing the borders of the chapters – including scientific studies and reflections – seeking for the overall conclusions.

Towards universal design for research

Nind unravels the differences and entanglements of different kinds of inclusive research (Nind, 2014), see Figure 49.

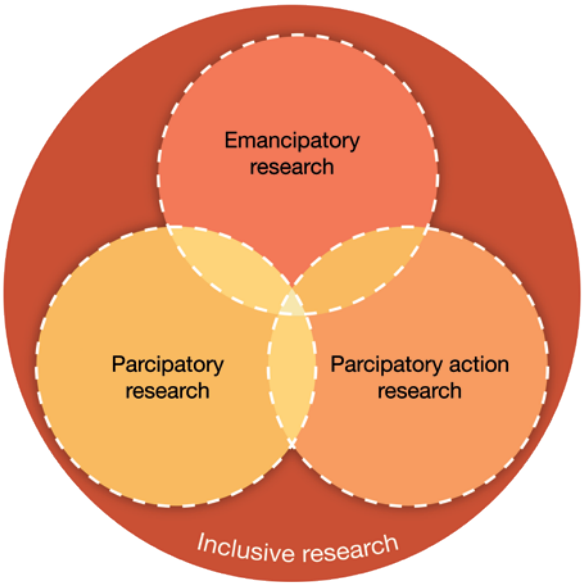

Figure 49: What is inclusive research? © René Krewinkel

From A family of overlapping approaches, by Nind, 2014, p. 10. Adapted by René Krewinkel and reprinted with permission.

Participatory research refers to the fact that experts by experience are involved in the process of doing the research work, rather than just providing data for it. In emancipatory research the experts by experience are not only participating but they are in control *"towards achieving their liberation"*. In Participatory Action Research (PAR) the emphasis is on the process, on seeing people as change agents. Through our research process we discovered that we stopped talking about 'us' being an inclusive research project. We worked as just a bunch of people, 'a gang', working together. In fact, some colleagues found it stigmatising to frame our work within the inclusion concept (see also Chapter 4, Collective Biography article on Collaboration).

With the term 'including people' the power imbalance begins. Inclusion is often defined as the process of bringing in those who are outside the scope of democracy and must be taken in by those who are already inside (Biesta, 2019, p. 113). Rancière critiques this is a colonial way of conceiving democratisation (Biesta, 2019, p. 117): democratisation is not a

process that starts in the centre and spreads to the margins. I agree that inclusion is not simply the process of including a group that was previously excluded. It is the formation of a new group as a group with a specific identity that did not exist before. Once our Cabrio research group was formed, we did not want to speak of it as an 'inclusive group' because it felt not right and even insulting.

We concluded that at the start of our research project researchers may search for companions (experts by experience and many others from different field) but once a team, it is better to speak about a transdisciplinary team (see Chapter 5). In our training we also do not focus on training (of competences of) persons in research but on training the transdisciplinary team as a system.

We already elaborated (see 6.1) on the importance of careful use of language and the risks of labelling people within one identity. That is why we purposely added another circle (see Figure 50) around the circles presented by Nind (2014).

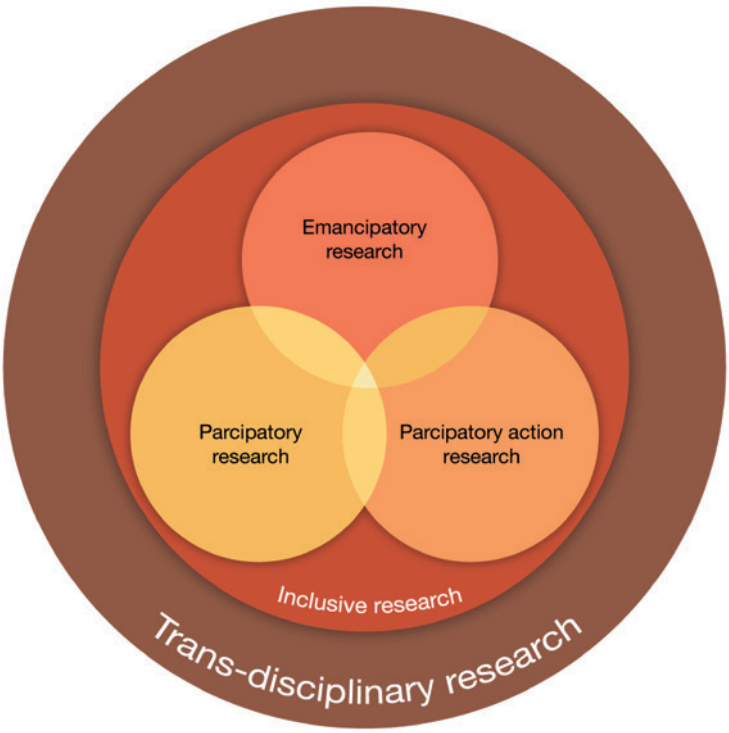

Figure 50: Adding a circle to Figure 49 © René Krewinkel

We embedded 'inclusive research' within the 'transdisciplinary research field': working together in a diverse community in which different kinds of (scientific, practical, tacit, experiential) knowledge are entangled and complement each other (Groot & Klostermann, 2009; McDonald & Stack, 2016; Buchner, Koenig & Schuppener, 2016). It is key that researchers with disability experience belong to the team from the start and are – as when relevant and without pressure – involved in all research processes. It is important to provide the right space and context for experts by experience, and for all researchers involved, in order to communicate and contribute, a finding that is reflected in literature (Nind, 2014; Embregts et al., 2018).

The very first page of this dissertation is in braille, a language many people don't understand. This confronts the reader with not knowing and needing somebody else with knowledge of braille to get access to the content of the page. This is what transdisciplinary research is about: knowing that you do not know and therefore you need others, within a research environment that is suitable for all. But this is hard work… so the first question is *"Do you really want to understand what is on the braille page?"*.

In the below sections we elaborate further on our findings through metaphors guiding us from the start of our research work in a Cabrio and bringing us to the finale in an Air Balloon. Based upon this text, Chapter 7 was created: a film that bring our findings and metaphors alive and accessible to a broad public.

Why choosing for metaphors?

Before we start enumerating our findings through metaphors, I want to explain the use of metaphors in this section and in our research work as a whole. From the work of Lawrence-Lightfoot and others (Lawrence-Lightfoot & Davis, 1997; Boelsma et al., 2017) we learned about the power of metaphors. We decided to create the Cabriotraining by using metaphors for different reasons. Firstly, the metaphors not only helped in understanding abstract terms and content and secondly, they also help in remembering and recalling information. We developed the metaphors on the road and the designers in our Cabrioteam drew them so we could embed them in the training, in our articles, in this conclusion section and in Chapter 7. I realise that metaphors don't work for all people, but I hope the text related to the metaphors helps to understand this section.

Metaphor 1: The Cabrio – cruising through the Sushi

Figure 51: The Cabrio © Sanneke Duijf

Henriëtte Sandvoort and I worked together for four years. In those four years we collaborated with a large and diverse group of researchers, designers, trainers, some of which also have experiential knowledge.

This brings us to the Cabriotraining we worked out for transdisciplinary teams (Chapter 5). The themes that we deal with in the Cabriotraining are divided into 6 modules. Each module was created based on literature, personal experience and upon the questions we received from research projects during the 4 years that Henriëtte Sandvoort and I provided trainingsessions to teams. Together we travelled through the Netherlands, but we also travelled to Belgium, England and Scotland for congresses and research meetings. While traveling we reflected on our own collaboration (sushi-layer-one), on the encounters with other researcher duos (sushi-layer-two), on the training sessions we gave to Dutch research groups (sushi-layer-three, on the experiences in The Netherlands and abroad when traveling and working together (sushi-layer-four).

Five reasons why we use the CABRIO-metaphor[12]:

1. **You can multitask easily in a Cabrio**

   "In a world where we seem to be increasingly busy, you can multitask with a convertible: catch up (reflect), freshen up and top up your tan on the way to your destination."[13]

   Multitasking in inclusive research is a major issue: A lot of time must be spent on building a relationship and shared understanding of each other, opening channels of trust and interaction (Cocks, 2006). Researchers involved must make themselves as transparent and accountable as possible, engaging in *"continuous efforts to embrace reflexivity within the research process"* (Cocks, 2006, p. 261).

[12]Translated from https://www.kennispleingehandicaptensector.nl/nieuws/onderzoek/gewoon-bijzonder/ervaringsdeskundigheid-cabriotraining-netwerk-samen-werken-samen-leren

[13]Translated from https://www.kennispleingehandicaptensector.nl/nieuws/onderzoek/gewoon-bijzonder/ervaringsdeskundigheid-cabriotraining-netwerk-samen-werken-samen-leren

2. Everything fits in, including a giraffe

The car seat area of a Cabrio is unlimited in height. So, with regard to the materials, methods and communication strategies we develop for research: we are invited to step out of comfort zones and bring along more diverse and alternative ways of researching. Working towards Universal Design for Research (Williams & Moore, 2011) asks for engagement with our own uneasiness (see Chapter 3: Roundtable Article) and our own struggle with the rather small academic comfort zone. This relates to the work of Kliewer, Biklen & Petersen (2015, p. 24) who state: *"Rather than blaming an individual's intellect for difficulties with performance, the presumption of competence directs attention to the educator who must find ways that allow for the demonstration of competence; in absence of success, the presumption of competence impels the educator to keep searching for new ways of engaging and connecting".*

3. Entry-level alternatives

With a convertible you can get in from any angle: people with different forms of knowledge and experience can enter the research team from different angles, experimenting and bringing in more perspectives and vibrant dynamism in the research work. Duggan (2020, p.13) attempts to rethink with his project 'the co-productive imagination' the co-production of research as complex, creative and eventful, disrupting spaces, relations of power and authority: *"The appetitive drive determines a restless search for difference and diversity in, for example, the backgrounds and experiences (…) and in the thoughts and feelings, experiences and encounters, media and modalities, and regimes of practice we explore. We are not triangulating findings nor applying tested methods but endlessly experimenting, adapting and following emerging findings wherever they go."*[14]

4. A Cabrio stimulates science

"With an open roof you have more contact with the atmosphere around you: being in close contact with the sounds and smells of your environment and the natural elements."[15] With inclusive research you bring in new voices and perspectives, making and rethinking theory in relation to living knowledges (Facer & Enright, 2016). This means we need to come to terms with the messy realities of inclusive research (Gristy, 2014). In our research we found that people struggle with this messiness, with giving up control, with this open roof that allows many intrusions and unforeseen happenings. In the training we include this insight, warning people for this to happen, creating room for reflection upon this theme.

[14]Translated from https://www.kennispleingehandicaptensector.nl/nieuws/onderzoek/gewoon-bijzonder/ervaringsdeskundigheid-cabriotraining-netwerk-samen-werken-samen-leren

[15] Translated from https://www.kennispleingehandicaptensector.nl/nieuws/onderzoek/gewoon-bijzonder/ervaringsdeskundigheid-cabriotraining-netwerk-samen-werken-samen-leren

5. A Cabrio promotes your relationships

Advertisers use it: in a Cabrio you only see smiling people. Chalochanová et al., (2020) wrote this to the subject in their accessible summary: *"We learnt that it takes time spent alongside each other to build good research relationships, and it depends on having fun together as well as working."* In the trainingsessions and in our research work we discovered the importance of humour and having fun together, this is also explored in our article on collaboration in Chapter 4.

In connection with the metaphor of the cabrio we conclude that, along with the fun comes building the personal relationship, building up a common history together. These factors provide the basis for the collaborative work to come.

Metaphor 2: A larger suitcase

Figure 52: The large suitcase with diverse research methods and communication strategies © Sanneke Duijf

A Cabrio can house a very large suitcase with diverse research methods and communication strategies. With the Cabriotraining we searched for more suitable, non-stigmatising approaches and devices that could support people in revealing their stories and experiences based upon the work of colleagues (Fullana et al., 2014; Coemans et al., 2017; Liebenberg, 2018; van der Vaart et al., 2018). In the 'Working Together, Learning Together' research project, we observed inclusive research projects struggling with communication, with design of easy-read versions, with the writing up of documents and with the use of illustrations. We share the struggle in our own collaboration, striving for adult-oriented easy-read materials confronting risks and dilemmas when making their research work accessible: simplification carries a risk of 'dumbing down', which could show less respect for experts by experience. In our struggle to design a stigma-free context we learnt that co-creation with designers, filmmakers, photographers, … can generate a way-out for

researchers. The artists can support researchers in leaving their comfort zone of words and language as only form of expression. Working towards universal design for research in transdisciplinary teams requires *"a necessary space for academics and communities to challenge elitist and exclusionary knowledge production cultures. It invites us to unlearn the inheritances of academia as a society of letters. It is the space to explore research practices that venture 'beyond text and academia's logocentrism, work 'beyond critique' and construct just alternatives in and with communities"* (Duggan, 2020, p.2).

Metaphor 3: The research kitchen

On the road, in our Cabrio, with our large suitcase, we visited many colleagues and teams engaged in inclusive research. We met them in their research kitchens and were invited to their table.

In the Cabriotraining we introduce this theme in the introductory module through the metaphor of the research kitchen: Who decides on the menu and the ingredients; how are tasks divided over the team, who gets in and out, who cannot be missed in the kitchen, are we allowed to make failures and what happens if we do?

Metaphor 4: The table within the research kitchen

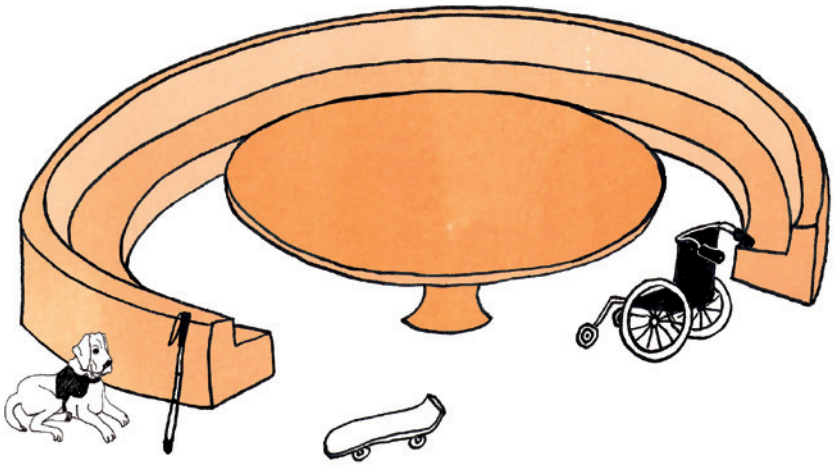

Figure 53: The research kitchen table © Sanneke Duijf

On the journey of my dissertation, I started with the idea that some experts by experience who are not able to express themselves in a verbal way, are not being able to keep up with the pace and means of academic research work needed coaching through support and training. I learned that inclusive research is NOT about ADJUSTING research in such way that people with disabilities can be INCLUDED by those who already belong. It is

about creating an environment, with a 'Table for all' in order for a variety of people – a transdisciplinary team – to be able to work and struggle together.
Cook (2009, p. 17) speaks about the messiness this work brings along: "*'The messy area' itself is unsettling, worrying, exciting and challenging. It is disruptive of habit and custom. The purpose of entering this mess is to enable and allow new directions to emerge; to enable diversity and multiplicity to work together to challenge the given, to recognise the nearly known and to support the creation of trustworthy, transformational knowing.*"
Our research revealed the importance of opening up on doubts and failures. This 'being ok' with honest opening up on mistakes fosters learning processes and the creation of a more failure free environment in which all team members can flourish and contribute.

Within the trainings, this safe space was also needed to be able to openly discuss the theme of tokenism: is participation 'real,' do people feel they belong and can contribute, and is their work validated? Unless all participants feel safe airing their views, this kind of discussion risks being tokenistic itself. We discovered a lot of binary thinking in our own data and notes: for example, in speaking about 'researchers' and 'researchers with experiential knowledge', as if all researchers are not also experts by experience in many fields. We also discussed the opposite: we all do research, but who get's called the researcher? We struggled with the sterile dichotomy that is deeply anchored in our society and language but also in our own thinking, in our own project: people with and without disabilities / researchers with and without expertise by experience… (see Chapter 4). Many discussions led us to the concept of transdisciplinary research and co-creation. We introduce this change in our thinking with the metaphor of 'the table for all', depicted in Figure 1, Figure 53 and in the cover of this book (Figure 54), created by Saar De Buysere.

Figure 54: Cover

Exploring and valuing the role of every person working in a research team asks for mutual understanding, and thus diverse methods of communication. In my introduction I quoted Nind and Vinha (2014, p.41) and I requote again because it is an insight that we share and evaluate as a major issue: *"Problems associated with inclusive research do not lie with people with learning disabilities."* I read in my fieldnotes some sentences I wrote down after giving a training:*"The meeting was almost starting. I saw one of the experts by experience coming in. He was trembling. He turned around to find a place to sit. His back was all wet. As he started talking. As he had missed a train, he was scared to miss the meeting."* (Sergeant, 2017, September 5)
Organising inclusive research also means thinking together about preparing rooms and tables, organising transport and support when needed; scheduling meetings

- at comfortable times matching with energy and day rhythm;
- that match with communication needs;
- that occur in good (silent, illuminated, well-equipped, accessible) locations;
- that offer enough quality break time.

Our data indicates it can be hard for researchers to get into contact directly with experts by experience, to find them, and to invite them for research work (Sergeant & van de Merbel, 2019). So 'getting in' in research work is already a big step for people. At the same time, we must also make sure people can get out without losing face, as is also indicated by Woelders and her colleagues (2015). This brings us to the work of Cocks (2006, p. 260): *"If you purposely work at gaining trust and building friendships with those who rarely experience this level of intimacy, you must prepare them for your departure when the work is complete"*. We embedded the dialogue on the entering and the leaving of the research kitchen in our training.
In our Cabriotraining we included debate on different questions, for instance:

- Technically, there are no people 'outside' our society, but some people don't want to be 'included' and need space to do so. How do you handle this in your research team and in 'including experts by experience, seeking participants for your research'?
- In some domains there are serious situations of exclusion of people with disabilities. Before we can work on inclusion, we need to investigate the shocking reality of exclusion. Have you come across this in your research work? How do you deal with the abrasive stories?

Sitting at the table we enjoy not only dialogues but also food together. In the Cabriotraining, we sometimes started to talk about the value of 'disability experience' by eating pancakes together. We explain why…

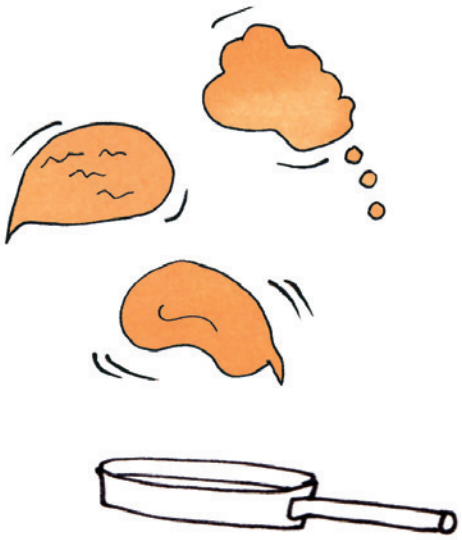

Figure 55: Catching stories © Sanneke Duijf

A key element in promoting inclusive research relates to the possibility that *"people are free to express their point of view with their own voice, that their perspective be respected and their work adequately acknowledged"* (Gill, 1999). (Fullana, Pallisera & Vilà, 2014, p. 724) In our training we use the metaphor of 'tossing the pancake' in the research kitchen to exchange and reflect on this theme, on the danger of data-robbery (stealing the stories shared by experts by experience without acknowledging their ownership) and tokenism (Nind, 2014; Embregts et al., 2018).

When experts by experience come forward to speak and share their story (throw up the pancake), who catches their story (catch the pancake)? Who makes sure it can land and be served in a tasty way? The throwing up of the story is an effort that takes energy and emotional work. What happens with peoples' story? Does it have any impact? Do people get credit for their stories? Michelle Fine warns about the risks of colonising the other in qualitative research (Fine, 1994). Or to put it with the words of Elisabeth Saint-Pierre: *"to present our participants to our readers on a silver platter for the sake of knowledge"* (St. Pierre, 2014, p. 7). Iris Young makes a useful distinction between two forms of exclusion: external exclusion (which is about how people are kept out of the process of discussion and decision-making) and internal exclusion (where people are formally admitted but, for example, notice that their claims are not taken seriously) (Biesta, 2019, p. 110).

The throwing up and landing of stories by people with disability experience is not all rosy. It can be a very abrasive process: people saying things that are shocking, 'not suitable' or

'inappropriate'. To stay with our metaphor: the pancake sometimes is smashed in the faces of the public. And then all present need to deal with the uneasiness of this situation, to face the harshness of the stories, to come to terms with giving up control… So, the knowledge of people with disability experience does not always romantically fit with scientific knowledge: they can be very 'against' each other, clashing with each other, evoking disharmony (Rebergen, 2017). In some groups, this knowledge might therefore not be wished and not welcome (Boumans, 2012; Kool, Boumans & Visse, 2013). From my dialogues with Jacqueline Kool and with Cabrio team members Henriëtte Sandvoort and Bob van den Berg, I learn that the experience of exclusion can be a very disruptive experience. I want to add this to my dissertation because I want to make clear that co-creation and transdisciplinary work often is not a harmonic togetherness and we 'simply' need to learn to deal with this (and not to brush it out of the way). This brings me to the quote *"May I question the disability experience?"* (Boumans, 2012), a quote we have embedded in our Cabriotraining to reflect on, together.

In the research kitchens we visited we learned they use also the participation ladder for measuring the quantity and quality of the work done by so-called co-researchers. Bigby, Frawley and Ramcharan (2014) identify three over-arching approaches: (1) where people with intellectual/learning disabilities *"act as advisors to researchers, governments and organisations about research agendas, conduct or dissemination of research"*; (2) where people with intellectual (learning) disabilities act as *"leaders or controllers of research"*; and (3) where they act as *"collaborators in specific studies with researchers without intellectual disability"*. When providing coaching and training to inclusive research teams, we observed variation in intensity of cooperation, and in performance of roles and tasks. In the training we explored how collaboration can be designed, what works and what doesn't. We had discussions about the limits to what someone can handle, on what responsibilities are suitable or not. Participants shared that having time for this dialogue on expectations, on matching competences and knowledge with research tasks was very helpful.

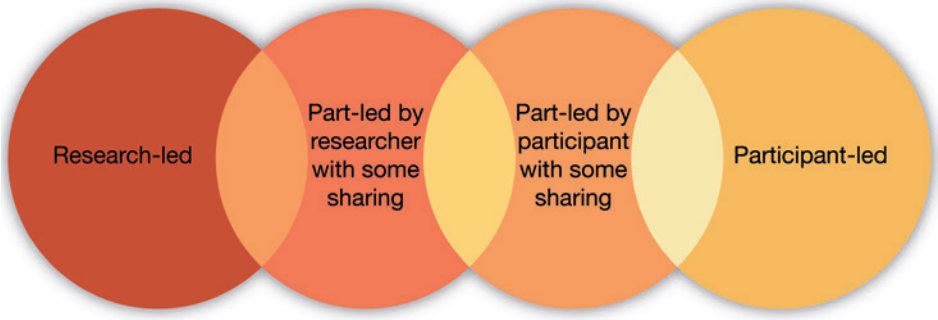

Figure 56: A continuum of overlapping approaches. © René Krewinkel From: A continuum of overlapping approaches, by Nind, 2014, p. 11. Restyled by René Krewinkel and reprinted with permission.

We also noticed that research projects evaluate the position of each member in the process, by building further on the work of Nind (2014) see Figure 55 and on the participation ladder (Arnstein, 1969). This evoked discussions on the danger of using this 'instrument', because it may suggest that higher levels of participation are always better, ignoring the changeability of each person's energy level and their learning processes. We suggest therefore to flatten the ladder or to leave it in the shore: it is not about the more participation the better but about real non-tokenistic collaboration (Embregts et al., 2018).

Metaphor 5: An adventure

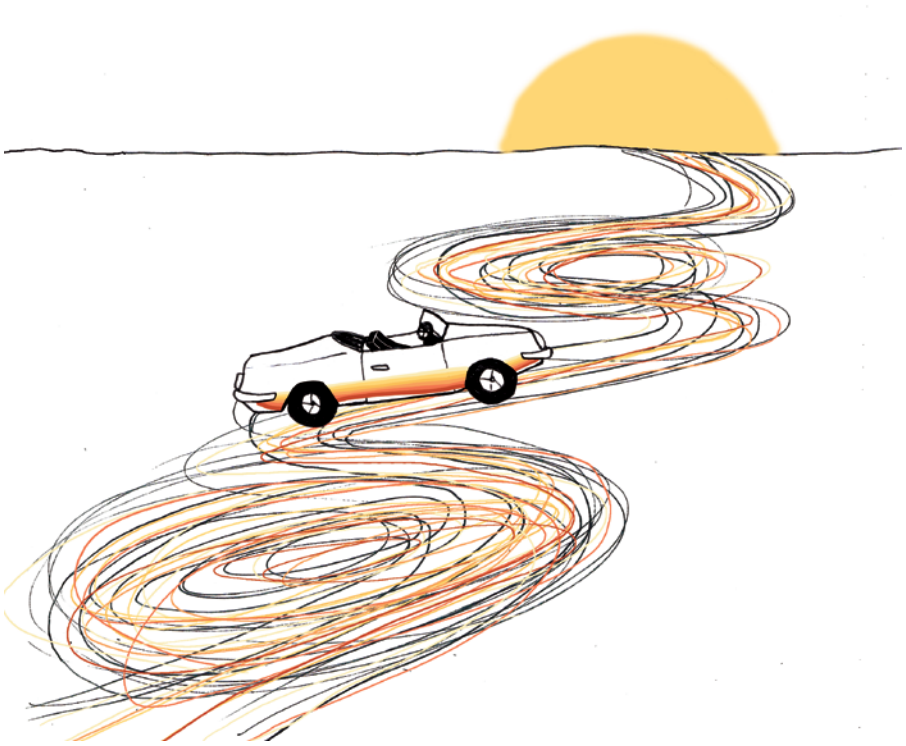

Figure 57: An adventure © Sanneke Duijf

In a Cabriotraining I asked one of the participants – Marianne Geboers[16] – how she looked at the meaning and significance of inclusive research. Marianne herself was diagnosed with autism. She says she needs some time to let a question come in, think about it and formulate an answer. She took this question with her and thought about it at home. In the next training session, she gave us this poem about how she experiences participating in inclusive research.

[16] Marianne Geboers explicitly gave consent to print her name with her poem in this article. Marianne wrote the poem in Dutch. We translated the poem into English for this article.

Together
Black-curved backs consulting
In a circle on the dune top,
They do not take root in loose sand.
Prepared for catching, they wear
the cloud cover on their shoulders,
Adventure comes falling from the sky.
Together they know everything.
Together they are not afraid for things in the dark.

Struck by this poem we talked on the meaning of her words in many occasions. *"Adventure comes falling from the sky"* brings us back to Chapter 5, to our design process in building up the Cabriotraining together. We often had the feeling of 'flying in the dark'. Atkinson and Claxton (2000) refer to this state of being in the following terms: *"the importance of not always knowing what you are doing"*. For researchers this can bring feelings of uneasiness and loss of control. This concept of uneasiness is also discussed in Chapter 3, within the theme of creative research methods.

6.2. Signification of language in the field of inclusive research

"Language is the precursor of action.
Therefore: be careful in your use of language."
(Angela Merkel, 2020)

From labelling people with a research group towards 'working in a gang'

"In Disability Studies, a new language is evolving to describe researchers: the term 'university-based researcher' is used and those people who engaged in academic research activities are referred to as 'co-researchers'."

(Stevenson, 2014, p. 24)

We learned from our research that we have to be careful with naming and framing people (see also 6.1). Henriëtte started in this project as a 'co-researcher'. She always introduced herself as co-researcher, a person with disabilities working in research. As we worked together as along-siders (Chalochanová et al., 2020), Henriëtte learned more about the research work. We learned to be careful with framing people within one identity, based upon their education, experience or background. Our experience may be rooted in (academic) education, in daily life, in professional life but often in the midst of all these categories of experiences. In other words: we all have these different kinds of experiences and how this 'mix' looks like depends upon the person. The word 'co-researcher' we don't use any more in our team (see Chapter 4). Henriëtte tells me this word gives her the

feeling of being a lesser partner in the research work. The colleagues with academic background in our team are named 'researchers'; only those researchers with disability experience are called 'co-researcher'. The word 'co-researcher' feels like a new label to Henriëtte. She feels the enhanced danger of being differed from 'normal' society being limiting on rights, opportunities and social power (Link & Phelan, 2014).

In our articles we were struggling with binary language using terms like 'people with expertise by experience' or 'researchers with experiential knowledge' versus 'researchers with academic background'.
Kool (J. Kool, personal communication, October 14, 2020) recommends using the term 'people with disability experience' because firstly, this experience is the reason they enter the research work. Secondly, the term 'disability experience' refers also to the experiences of disabling situations, to oppression, stigmatisation… However, we do need to stay aware they also bring other kinds of experience and knowledge which are also worth exploring. The intense collaboration in our transdisciplinary Cabrioteam – our 'gang' – and the dialogues with Jacqueline Kool inspired me to think about my own 'disability experience': growing up with my grandmother with major psychological problems and having a daughter with a metabolic disease. I began to realise that these life experiences have contributed to my deeply rooted awareness of the inherent complexity and entanglement of life experiences and knowledge. The forlaying research work confirms my own life experience that the binary language juxtaposing people with and without disability expertise does not do justice to this complexity and entanglement (Kool, Boumans & Visse, 2013). This research taught me it is often the person with disability experience who is 'on the surgical table' and the person with academic background stay 'in the safe zone'. Juxtaposing the role of the expert by experience and the role of the academic researcher causes the risk of completely disempowering the non-academic and at the same time alienate both sides from each other. Therefore, with Michelle Fine, we urge researchers to engage in social struggles with people who have been excluded; 'to work the hyphen' in revealing more about ourselves and about the structures of this othering (Fine, 1994, p. 72; Chapter 4).

From 'inclusive research' towards 'transdisciplinary research'

The same process was observed in our transdisciplinary team whilst building up the Cabriotraining. After a while we stopped calling ourselves 'inclusive' because it felt humiliating: we were just a group of people with very different background and knowledge (for the definition of transdisciplinary team: see Chapter 5) creating and struggling together.

"Social inclusion is conceptualized as the experience of being recognized and accepted as an individual (in spite of differences), having interpersonal and reciprocal relationships, and belonging to a group."

(Cobigo et al., 2016)

Academics and activists rooted in the Disability Studies field use the term 'inclusive' to talk about exclusion and to work towards a stop of this exclusion. In conclusion, 'inclusion' is used when 'exclusion' is at stake. From the moment there is a joint venture and people are working/creating/living together, there is no point in framing this with the term 'inclusion'. In particular, from our research we learned that this term can differentiate and devaluate your mainstream transdisciplinary collaboration.

6.3. Limitations

We will structure the limitation section using our so-called sushi-model.

The heart of the sushi: Close collaboration between Henriëtte Sandvoort and Sofie Sergeant

In the project 'Working Together Learning Together' the participating researcher duo was involved in the iterative spiral of data collection, data analysis, planning and implementing action and critical reflection. Our action research method was used for improving practice of inclusive research and for developing training for research projects. One of the main criticisms of action research is the problem of subjectivity (Kock, 2004) because there is a tendency for the researcher to be over-involved: personal biases might come into play in all the phases of the research work. To overcome this inherent risk within action research, we have held logbooks and this way we made our research process as transparent as possible. Secondly, we never have done anything unchecked: we always have expanded our team, asking for advice and feedback, letting our work check in every phase, always engaging in analysing the data in a larger team.

The second layer of the sushi: Collaboration with two other researcher duos

Chalochanova and colleagues state that *"further reflection is needed to explore how alongsider research by people in close, long-lasting working relationships permits or inhibits disagreement and difference, possibly through inviting an observer to research meetings and conference presenting, with a view to commenting on the way power is used."* (Chalochanová et al., 2020, p. 155)

This dissertation departs from this call for reflection of Chalochanová and colleagues. We learned that it is important to acknowledge the difference in background, in experience, in literacy… and to reflect on this, because this has a huge impact in how the research starts of and continues. In the Collective Biography article, we have made a start on the theme of power within the relation, but we have not done power analysis as such. This is something we would like to explore in future research work.

The third layer of the sushi: 10 Dutch research projects funded by ZonMW

- We realise our findings are based on a relatively small amount of research teams, all based in the Netherlands. The research teams were obliged to conduct their research work inclusively, this was ordered by the funding organisation ZonMW. This might have had influence on the intrinsic motivation of the research members an on the process of the training.
- In reflecting on our own work and position we connect our stories and put emphasis on what inclusive research requires from researchers in line with Walsmley (2004) who examines the roles of all researchers involved in inclusive research. What lacks in my dissertation is an in-depth analysis of what this inclusive research involvement means for all researchers involved. Student Rosa Stalenberg made a start with her research work in unravelling this theme. In the near future we will build further on the work of Stalenberg (Stalenberg et al., 2020).
- We have created the Cabriotraining in an iterative design process, we have organised informal evaluation sessions and ongoing reflection. But we have not yet set up an evaluation study of the value of our Cabriotraining. This is planned – also due to COVID-19 – for 2021 and the following years.
- In our research group we experienced that giving the training in duos has many advantages: if feels safe, it gives opportunities for close connection and collaboration. We are now training new duos to give the training. We believe the trainer duo is also crucial in the outcome of the evaluation of the training sessions, but we not yet have researched this matter.

The fourth layer of the sushi: The research field and the social structures in which we operate as researchers

We have created the Cabriotraining for transdisciplinary research teams. But we do receive questions from other fields for training. Questions come from different domains: education, care, public transport, tourism, architecture, politics…

We have not yet enough experience with these questions coming from different field then the research domain. In future we plan research to investigate and evaluate this evolution.

6.4. 'Cruising through the sushi': Implications for practice & research

As put in our Introduction section, Nind and Vinha (2014, p. 40) identify four barriers in doing inclusive research. Along the road of our own research project, we spoke with many (inclusive) research teams. Researchers recognised these barriers and agreed that collaboration between researchers with academic background and researchers with experiential knowledge can be difficult because it is a new experience to the team: they never had to work inclusively, not in school, not in leisure and not in work. The teams encountered many bumps as I wrote in a column based upon my research diary notes: *"Searching for people. Retaining people in the team. The search for good communication, appropriate working methods, creating a saf e context. People spoke to us also about the intensity of inclusive research work, the proximity of the life stories and the experiences of stigma and exclusion."* (Sergeant, 2019, June).

We will now give insight in possible implications for practice and future research on how to tackle attitudinal, social, material and interpersonal barriers, based upon what we learned from our own research project. Before assigning our implications to one of the four barriers we want to stress that our research taught us that all barriers are connected and interdependent. You cannot tackle one barrier at a time.

Attitudinal barriers

This concerns *"funders' lack of knowledge or understanding, their inflexibility, their low expectations of what people with learning disabilities can do, and their failure to learn or change. There were also general attitudes about protecting people with learning disabilities or not valuing their input."* (Nind & Vinha, 2014, p. 40)

It has been found to be important that programme committees evaluating (inclusive) projects recognise the value of inclusive research and have knowledge of the conditions and characteristics of inclusive research.

In working closely together with Henriëtte I noticed how many times people treated Henriëtte in a stigmatising way: they spoke to me instead of directly to her, they spoke in a childish way to her, they asked when the researcher would turn op when she interviewed them… In our research group we often discussed the theme of 'stigma', 'self-stigma' and 'associative stigma' (Scior & Werner, 2016; Nieweglowsky & Sheehan, 2017). Personally, I noticed that arriving on a congress, in a hotel or to a party with Henriëtte resulted sometimes in less social contact and people avoiding us. We recommend for future research to look at 'associative stigma of disability' – how nondisabled individuals are

affected when they associate with the stigmatised group (Nieweglowski & Sheehan, 2017) – and what it means for inclusive research teams.

> *"Rather than blaming an individual's intellect for difficulties with performance, the presumption of competence directs attention to the educator who must find ways that allow for the demonstration of competence; in the absence of success, the presumption of competence impels the educator to keep searching for new ways of engaging and connecting. Connectedness and the presumption of competence contests all that mental retardation has represented and brings us to the end of intellectual disability."*
>
> (Kliewer, Biklen & Petersen, 2015, p. 24)

I include this quote again, because I believe this is crucial in inclusive research. *"People with intellectual disabilities are stigmatised throughout the course of their lives"* (Nieweglowski & Sheehan, 2017). This stigma marks them as different and places them in the role of receivers of care. What can happen in a transdisciplinary research teams is that people feel competent, able to give and to contribute. And this changes something in their lives, in the lives of their families and allies. Additional research is needed to explore this impact and the ethics: what if the research project stops; to what end at are researchers responsible for their colleague researchers with experiential knowledge.

Stating that people with disabilities have the right to participate, to belong and to have a good quality of life is not enough: communities must also create spaces to enable this (Turnbull et al., 2002). 'Spaces of encounter' need to be created (Meininger, 2013). Moreover, we found it is crucial to create a safe environment where all research partners feel welcome, feel a sense of belonging (Schippers, Bakker & Peters, 2018), and are able to contribute. Researchers reported to us that this is very difficult within the highly verbal, abstract, hierarchical and competitive academic world. We saw researchers struggle to be 'number one' in the hierarchy. We saw experts by experience struggle to be 'the less disabled one', to be on top in the disability hierarchy (Deal, 2003; Scior & Werner, 2016). This finding is related to the finding that research teams face problems in finding researchers with experiential knowledge to staff their research team. They seem to be protected by their gatekeepers (Sergeant & van de Merbel, 2019; Sergeant, 2019). Moreover, as researchers look for experts by experience, it is tempting to look for people who can easily be integrated into their common way of communicating and researching. In this way people with a quieter but very interesting voice are (again) excluded. Therefore, active change management need to be applied (Brown, 2017; Schippers, 2010) to employ meaningful inclusive research projects.

Barriers in the social process

This relates for instance to *"the barriers put up by universities protecting their territory, inaccessible calls to tender for projects and few routes into research for people with learning disabilities. Some barriers were put up by individuals and some were rule-based such as rules about tenders, formal ethics and governance requirements, online submission to journals, and the need for police checks."*. (Nind & Vinha, 2014, p. 40)

Related to the barrriers in the social process we purpose four ways to empower inclusive research: safe research environments, learning communities for all, research platforms and inclusive universities.

1. A safe research context that enables people to grow and develop competences (Biklen & Birke, 2007; Frankena et al., 2019) is necessary for every person in the team. A safe research context (see Chapter 5 and the concept of Level Zero) has a broad range of possibilities and ways to co-create (van der Vaart, 2018). Research teams need to enlarge their repertoire of communication and research methods, stepping out of the verbal box and making way for more people to join research (MacDonnel & MacDonald, 2011; Coemans & Hannes, 2017). An important and wicked problem is the following: How can we create a safe research context in an academic world that is organised upon temporarily projects? We need to think about the moral and ethical implications of giving people with disability experience the possibility to contribute to research and to feel belonging and contributing in a research group whilst realising that the project will end and hereby possibly the collaboration and their contribution, their new and socially valorised role within a transdisciplinary team. We have experienced in our own research group the anxiety of colleague researchers with disability experience to 'go back' to their original work space. What is the role, the duty and the responsibility of academic researchers towards their colleague researchers with disability expertise leaving the project? In the Cabriotraining we bring up this wicked problem for reflection as early as possible in the project where we provide the training or coaching. In discussing this point with T. Teunissen (personal communication, November 30, 2020), she revealed her idea on creating a community for researchers with disability experience as a safety net, a support network, to share experiences.
2. Learning communities for all researchers and experts by experience involved: The world around transdisciplinary research is unequal and poorly accessible (Walmsley & Johnson, 2003). Not only people with disabilities, but large groups of people in our society see academic settings as a world apart, far from reach. In turn, academic workers are highly educated, but typically lack intimate knowledge of disabled peoples' communication systems, their living environments, and the barriers they face (Johnson & Walsmley, 2003). As we expected from previous research, we found

evidence researchers often are not familiar with co-creating with experts by experience. Further research is recommended.

3. Transdisciplinary research platforms: We observe a need for platforms where people engaged in transdisciplinary research can share and discuss their work. This means offering opportunities to learn and inspire beyond research-group boundaries. In future research, we want to explore this idea further.
4. Inclusive universities: University spaces were teams work towards more Universal Design for research (Williams & Moore, 2011): spaces that are created for transdisciplinary teams making use of multi-sensory and creative research methods and ongoing searching for what is needed for everyone to contribute and to flourish (see Level Zero, Chapter 5). In discussing this theme with Henriëtte Sandvoort, she came up with an idea. With her permission, I embed her idea in my PhD manuscript as an implication for practice and research in the future: *"We have worked together for four years. You can achieve a PhD based upon our collaborative work. This triggers me somehow. I would like to investigate in the future – with colleague experts with disability experience – how we could organise possibilities for ourselves to obtain a PhD grade in the future."* (H. Sandvoort, personal communication, October 19, 2020) This relates to elements of the capability model (Van der Klink, 2019, p.101-102): *"a) identification of relevant capabilities of the employee b) work conversion factors (i.e. factors in the work place that enable people to convert resourcers (means to achieve) into capabilities (freedoms to achieve) and functionings (achievements) and c) personal conversion factors."* How to enable people with disability experience to build their own valuable and valued PhD-project is a question Henriëtte wants to explore with others in future research. Because working towards universal design for research asks for opportunities for a diversity of people not only to contribute to research but also to be valued.

Material barriers

Related issues here are *"transport and information, lack of funding for preparatory work (which was important to the cherished value of involving people with learning disabilities at all stages), inadequate funding more widely, and rules associated with people's benefits payments making short-term paid research risky."* (Nind & Vinha, 2014, p. 40)

We propose to research in future ways to be able to fund and co-create in the design process. Now, funding organisations start giving funding when a research project is written, fully designed and honoured. After this start, research projects often start finding experts by experience. This way, the experts by experience and people from other disciplines and backgrounds are rarely inside the research team at the moment when the research agenda and important design issues (including practical decisions) are made.

Within-person barriers

This refers to communication and literacy difficulties, to improving the abilities, skills and knowledge of people and groups. (Nind & Vinha, 2014, p. 40)

To find a way to tackle this barrier, we developed the Cabriotraining. Organising the Cabriotraining will always remain work in progress. In searching for diversity-sensitive communication and addressing literacy issues we embedded and adjusted our app called Ebb[17] to fit better in the Cabriotraining (see Chapter 5). We created this application based on the visual research methods 'photo elicitation' and 'photo voice'. The app supports (self)reflection – with photos and images – on: 'Who am I? What are my talents? What do I need in order to florish at work?' The app Ebb will be evaluated in 2021 the Ebb on how the app can support communication and literacy difficulties and on how we can use the app in future inclusive research work.

As we are providing training sessions, we discover that other teams then research teams also show interest in the content of the training. We receive questions from architects, care organisations, municipalities and schools. So, the coming months we will engage in embedding more issues on co-creation without direct link to doing research together. Further research is recommended on how co-creation in care institutions, in architecture, in education, in policy and in all areas of our society can learn from inclusive research tradition.

In this manuscript we move from inclusive research to transdisciplinary research, aiming and striving for Universal Design for Research. In future research work I want to explore further on the 'hyphen space' (Collective Biography Article on Collaboration in Chapter 4): on how to break the dichotomies, and to go beyond the 'rooted in science' versus 'rooted in experience' split.

My research made clear that transdisciplinary research does not profit from disneyfication or from romanticising. Being aware of important conditions as enough shared ambition, enough time, energy, efforts, training, money, it takes for all research group members, engaging in transdisciplinary research demands for a clear rationale and added value (Strnadova et al., 2014). Awareness of the limitations of one's own field of expertise and the added value of knowledge linked to disability experience are crucial. Knowledge of professionals, scientists and people with disability experience may clash or at least there is some chafing. We recommend if you do not like this chafing, if you prefer smooth research, never engage in transdisciplinary research.

[17] https://ebb.works

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Chapter 7 – Air balloon

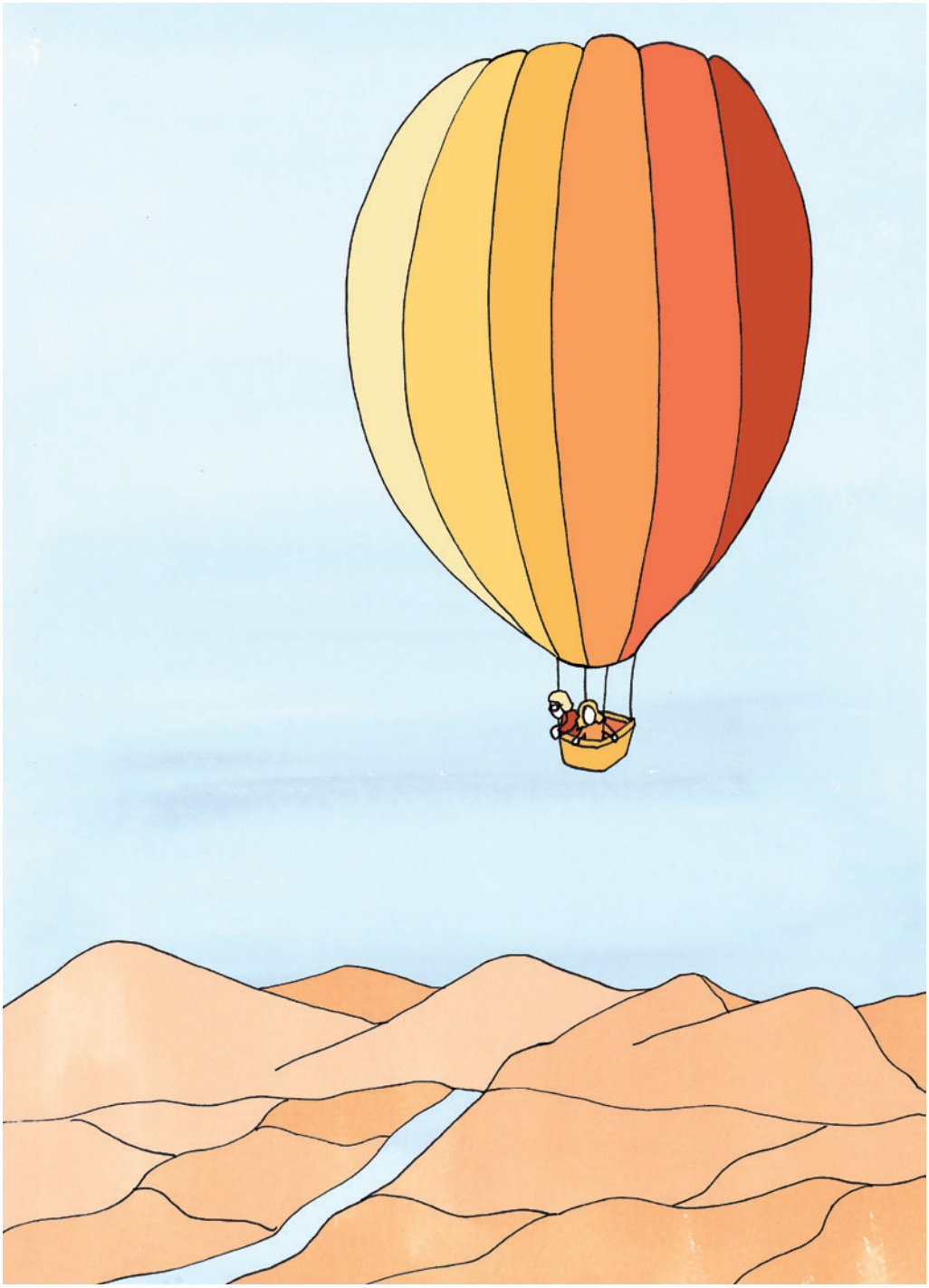

Figure 58: Henriëtte Sandvoort & Sofie Sergeant in an Air Balloon © Sanneke Duijf

During the four years of our research, we were allowed to take time and rest to get to know the research projects and to develop and try out training courses. We spent a lot of time together, we worked closely together (in a small basket) and we took risks, sailed through wind and weather, went out together, we left a place that was known but we didn't know where we would land…

In those four years, we had the chance to architect our own research space. This shared new space was negotiated with agreed rules and ways of working situated in context and time in which we were operating. This space can be called 'a messy social space' which can lead to problems, complexities and tensions but may also lead to creative solutions in response to these challenges (Seale et al., 2015). In creating the Cabriotraining we wish to contribute to how to establish, arrange and foster such 'third spaces' (Soja, 1996; Seale et al., 2015), spaces of encounter also referred to as heterotopia (Meininger, 2013; van Trigt et al., 2015).
We hope the forlaying research work contributes to the shift in power from academic researchers without disability to people with disabilities and to better quality of transdisciplinary research in research process and results.

The QR-code links to a summary of this dissertation captured in a film. We chose not to create an easy-to-read summary because that also excludes people from understanding the essence of my thesis. We chose for a film that gives a wide range of people the opportunity to understand what this dissertation is about, without too much effort. In the film we combine written and spoken words (Dutch and English), with music, sound and images. This way we want to make our research work more accessible to a diverse audience, not only in the research process but also in the dissemination and implementation of the research results. This is also the reason why I wish to defend my dissertation in Dutch: to make my PhD defence accessible for all the people who joined me in my research work.

Figure 59: link to Hot – Air – Balloon – Film

7.1. References

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Table of figures

STICHTING MARGUERITE - MARIE DELACROIX

Stichting van Openbaar Nut

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DE LOVIE

Werk Saam westfriesland

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versterkt waardegericht ondernemen

HELEMAAL VOOR JOU

LICHT EN LIEFDE

hulp voor blinden en slechtzienden

Joint Projects

DISABILITY STUDIES in Nederland

ZonMw

samen werken samen leren

Amsterdam UMC
Universitair Medische Centra

LFB

Tranzo
Wetenschappelijk centrum voor zorg en welzijn

MULTIMEDIA TEAM.NL

KENNISPLEIN gehandicaptensector

'Working Together, Learning Together' (WTLT) is the name of the nationwide inclusive research project in the Netherlands we conducted from 2016 tot 2020.

Within this research project, the PhD research work of Sofie Sergeant involved an inclusive and action-orientated reflective practice of developing training for other inclusive research teams. The PhD manuscript is built up upon a collection of five papers.

Two research questions are guiding:

- What are the catalysing ingredients and conditions for organising inclusive research in order to overcome attitudinal barriers, barriers in the social process, material barriers and within-person barriers?
- Based upon these ingredients and conditions: what kind of training and coaching is needed?

The forlaying PhD research work identifies and explores four conditions for inclusive research:

- Safe research spaces and sense of belonging;
- Room for collaborative learning and competence building;
- Multi-sensory communication and research methods;
- Time for reflection on power, ownership, vulnerability, prejudice, stigma, and the risk of tokenism.

The developed training is referred to as 'the CABRIO-training': a coaching and training program for 'transdisciplinary' teams consisting of researchers with academic background, professionals from diverse disciplines and research team members with disability experience.

Sofie Sergeant works as the education coordinator and researcher for the Dutch organization Disability Studies in Nederland (DSiN) and for VU Amsterdam, Medical Humanities. Her PhD project is rooted in a national project funded by ZonMW 'Working Together, Learning Together': an inclusive research project on developing training and coaching for inclusive research teams.

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